SAN FRANCISCO CHAPTER - LPA 1985

Creator – Donna Hughes

S12412

S12412

SEND TO DONNA HUGHES

Short Stature event set for June

Symposiumcoming up

By Ed Lang
LPA News Editor

For many LP's, the Short Stature Symposium is one of the more important medical, psychological and emotional experiences they will participate in throughout the year.

It offers members an opportunity to not only get updates on their physical conditions but to be a part of the various speaker panels dealing with a wide range of topics vital to being an LP.

I was privileged to meet and hear Mrs. Betty

Mrs. Betty Elder
...is co-ordinator

Elder of the Moore Clinic at Johns Hopkins Hospital. Two days after Mrs. Elder's visit to South Florida, I received a letter from Joan O. Weiss, senior clinical social worker and short stature consultant regarding the symposium. Here is a breakdown of the pertinent information regarding this big event:

The Eighth Short Stature Symposium, sponsored by the division of medical geneticas at John Hopkins Hospital, will be offered June 27-28 co-chaired by Joan Weiss and Betty Elder, short stature coordinator of the Moore Clinic.

Some of the new workshops being offered include Independent living, issues of divorce, adoption, parenting skills and workshops for senior citizens. The usual workshops are also being offered.

A Short Stature Clinic for medical management and syndrome identification will be provided on Friday.

Mrs. Elder indicated that the June 27 clinic is being limited to 50 people and it's on a first serve basis. Make an appointment as soon as possible.

For more information, you may write to Ms. Weiss or Mrs. Elder at the Johns Hopkins University School of Medicine's Moore Clinic, Baltimore, Md., 21205.

LPA NEWS

Little People of America

Volume 1 Number 3 **March 1980**

Plans take shape for convention

By Ed Lang
LPA News Editor

Are you making plans for "Convention '80 in L.A." We hope so because the months are ticking by at an unbelievable rate of speed. It seems like just yesterday when we were celebrating Christmas.

Charles Secor, Convention '80 in LA Chairman says we need to discuss several key items regarding the big event.

"First, we need to discuss the dates because everyone has been asking about them," Secor said. "The convention runs from July 21-25 at the L.A. Airport-Culver City Pacifica Hotel.

Continued on Page 2

Hotel Pacifica is convention site
...it is completely barrier free

3 convention food plans offered

Continued from Page 1

"Another item of major concern is the food prices. We have three plans this year to fit almost any income level. The first plan includes breakfast, lunch, dinner tax and gratuity Monday through Thursday as well as breakfast and lunch on Friday and the cost of plan-A is $104.13."

Secor sayd Plan-B costs $75.13 and includes lunch and dinner Monday through Thursday as well as lunch on Friday and all tax and gratuities.

Finally, the third plan, Plan-C will cost $43.88 and includes dinner Monday through Thursday as well as tax and gratuities.

"A children's menu will also be available for kids under 12-years-old," Secor said. The prices are as follows: Plan-A, $55; Plan-B, $40 and Plan-C, $20."

Reservations should be made as soon as possible and for those planning ahead, the rate for a single room is $41.93 per day including tax. Double, triple and quad occupancy rooms are $46.25 with children under 18 sleeping free.

"There will be barrier free accomodations as well as a free limosine service," Secor said. "Some of the events planned so far are a trip to Disneyland, Universal Studios, a beach outing, a movie character night and a visit to a TV game or talk show," Charles said.

The Convention Chairman has also requested all National Officers, District Directors and Chapter Presidents send in a resume and black and white photograph to him for insertion into the Convention Program. The address for Charles Secor is an follows: 1132½ 28th Street West, Los Angeles, Calif., 90005.

"We've also set up the prices for ads in the National Convention Program," Secor said. "It will cost $35 for a full page, $18 for a half-page, $14 for a third of a page and patron listings are $3 per person."

Secor has also announced other chairpersons for the Convention. "Patty Moloney is in charge of the Ladies' Tea; Charlie Rosenberg heads up registration; Kevin Thompson is in charge of sports; Evan Artram is the printing chairman while Al and Harriet Stickney are heading the parents auxiliary program and children's program."

'Another item of major concern is the food prices. We have three plans this year to fit almost any income level.' --Charles Secor, National Convention Chairman.

Secor added that if any member wants to bring his or her own doctor to the convention, they should write to Dr. David Sillence in care of the Harbor Hospital, UCLA Short Stature Clinic, 1000 West Carson St., Torrence, Calif., 90509. Doctors must be approved by Dr. Silence. Sillence is working through the Medical Advisory Board and he can be reached at area code 213, 533-3667.

The L.A. Chapter is hard at work on various fundraisers to pay for the convention including a visit to the very chic Flipper's Roller Disco in Burbank set for March 30. Also the chapter is selling a book titled "Helpful Hints," at $4 which is very useful for LPs.

In other Convention News:

The 1980 National Convention Committee had a meeting on November 11, 1979 at the home of Micky & Shirley Sosenberg. Special guests present were Al & Harriet Stickney from Oakland, Calif. and Dr. David Sillence from the Short Stature Clinic at Harbor - UCLA Medical Center. The purpose of this meeting

Continued on Page 3

Recommended by Billy Barty

LADIES, AT LAST!
A SHOE MADE JUST FOR YOU!!

"the GLASS SLIPPER" specializes in custom-made HIGH fashion shoes for little women. NARROW thru WIDE.
Write for our free illustrated brochure to:

the GLASS SLIPPER
P.O. Box 3044
North Hollywood, CA 91609

Staples shown on TV

DISTRICT ONE
(Me.,N.H.,Vt.,Mass.,R.I. and Conn.)

We're a little behind on District One news. The last we heard was that the November meeting was held in Keene, N.H. at the St. James Episcopal Church and the annual Christmas party was at the Kellers on Dec. 17.

Celeste and Al Staples along with Ruth Ricker were on the "At Noon" with host Ted O'Brien on WNAG-TV (Boston's Channel 7). We're told the show came out great and the Channel 7 crew even came to the Staples' apartment to film the folks at home.

Ann Brown and her family have left District One and now live in Colorado Springs, Colo.

With some good fortune, we hope to have more District One news in our next report.

DISTRICT TWO
(N.Y., N.J. and Pa.)

The New York Mets Chapter was scheduled to hold its chapter meeting January 27 at the home of Allison Alter of Manhattan. A meeting is now being planned at the New York University Medical Center in Manhattan in the spring.

The Chapter's holiday party was held at the Sheraton Poste Inn in Cherry Hill, N.J. in early December. A total of 37 members attended the annual event. Because of spiraling inflation, several couples including some district stalwarts, were not able to attend.

In other district news, there was a large gathering in the fall for the regional meeting. There were 50 people in attendance. Several parents spoke of the need to rejuvenate the Parents Auxiliary and according to District Director Beth Wason, "lists of auxiliary members will be compiled and hopefully a meeting may be arranged soon."

Election of district officers will be held at the Spring Regional in Binghamton, N.Y., and those interested should contact Beth Wason.

Beth reports that at last count, there were 300 members in District Two and the area is still growing.

In other news around the District, the Islanders Chapter had a Chinese Auction and several members

Circus star "Mich" with Mini-Gators
...he spoke to members before performance

District Reports

Bobby Van Etten (l) and Dr. Steven Kopits
...go over medical plans for Florida Regional

were in attendance. Their Christmas party was also a smash held at the home of Stanley Wermess.

There were seven members in attendance at the Garden State Chapter meeting at the Spectors in the

Continued on Page 4

Final plans underway for Convention '80

Continued from Page 1

was to develop a Children's Program, discuss Harbor - UCLA Medical Center Role Concerning workshops and the LPA Medical Advisory Board, developing a Parents Auxiliary Programs, the raffling of two Complimentary Rooms from the Pacifica Hotel, and the publishing of the Convention Photo Album.

Here are some details concerning the Children's Program, the Medical Program, and the raffling of two Complimentary rooms.

The Children's Program consist of:

—Early morning swimming lessons
—Two Children's Field Trips
a. The Children's Museum
b. Los Angeles School of Gymnastics
—Children's Films (Pyramid Films) with popcorn and soda or juice
—Teen Get Aquainted Party
—Playroom with Babysitting - We need toys and babysitters - contact Charles Secor (213) 747-2158.

The Medical Program consist of:

—Medical Workshops Tuesday Morning - no general membership meeting
—Membership Meeting - 10 - 20 minute Medical Talks by Dr. David Rimoin — Mon - Wed - Thurs meetings
—If you would like to invite your own personal **Physician to the 1980 National Convention, your Physician most contact Dr. David Sillence** for clearance. His address is: Short Stature Clinic, Harbor - UCLA Medical Center, 1000 West Carson Street, Torrance, Calif. 90509 (213) 533-3667.

Carol Kelly appointed historian

Continued from Page 3

late fall. The Garden State folks held their Christmas party at the Helen Rossettini home. Finally, from the Pennsylvania Dutch Chapter, their most recently reported meeting was at the Phyllis Chase home.

DISTRICT THREE

(De.,Md.,N.C.,S.C. and Va.)

The big news around these parts is the appointment of Carol Kelly of Warrenville, S.C. as LPA librarian and historian. The appointment was made by LPA President Gerald Rasa.

The Delmarva Area members met at Robin Zeltner's abode in Alexandria, Va. in November. The Chapter Christmas party was hosted by Cara Egan and her family in Silver Springs, Md. Santa Claus made his annual visit for the Little Littles.

In South Carolina, the 'Way Down South Chapter met in Columbia at the home of Christ Bauer.

There were few activities going on in Tarheelia Country but Ann Hinkson ran a nearly perfect political campaign that resulted in her election as a member of the Hildebran Town Council. Coulcilwoman Hinkson was sworn into office by none other than her husband, the honorable Magistrate Judge Bob Hinkson who also swore in the mayor and two other council members.

In early November, Beth Freeman (an all around nice person) served as hostess for the big district gathering in Charlotte, N.C. Frank and Frances Duckworth came up from District Four while Cy Agoss was on hand from District Two. Also present was Gerald Rasa and his First Lady, Kitty.

Harvey Gantt of the Charlotte City Council presented the group with a key to the city and at the banquet, several special awards were presented.

Beth Freeman was presented with a special message T-shirt and the district mileage award was presented to Dick Mowry of Seaford, Del. Poor Dick was lost for five hours.

There was discussion about the posibility of District 3 bidding for a national convention but nothing definite was decided. Everyone agree the weekend was a worthwhile and happy experience.

DISTRICT FOUR

(Ala.,Miss.,Ga., and Fla.)

What was billed as a "Winter Regional" meeting turned into a gathering of Florida members in West Palm Beach on Jan. 11-13. The gathering's purpose was twofold. First, it marked a vey rare visit of Orthopedic specialist Dr. Steven Kopits who flew in from the Hopkins Medical Center in Baltimore.

He held a major seminar with South and Central Florida physicians who wanted to familiarize themselves with Short Statute conditions. He also held a two day clinic with LP's and Little Littles.

The other purpose was a social gathering and we certainly did socialize. We attended one of the first showing of the Ringling Brothers and Barnum and Bailey Circus.

Assistant District Director Bobby Van Etten did an excellent job of coordinating the event and creating a lot of positive publicity not only for the two Florida Chapters but LPA in general.

Also, behind the scenes work for the Regional was done by Bobby's sister Paula Buerkle who even staged a benefit tennis tournament to help defray some of the weekend's costs.

District Reports

We were also very fortunate to have Dr. Kopits' able assistant, Diane Davis, as well as Mrs. Betty Elder, Short Stature Coordinator of Johns Hopkins Hospital's Moore Clinic.

Mrs. Elder filled the group in on the Short Stature Symposium to be held in June (see related story) in Baltimore. She also helped many members while she was in South Florida. Dr. Robert Bright of the University of Florida also was on hand and Dr. Jamie Frias, who was supposed to attend, came down with the flu.

The regional also received a very special letter from actor Burt Reynolds which you see below:

In other district news, the North Georgia Crackers had 28 members in attendence at Herb and Rachel's home in Georgia in November.

Plans for the April Mini-Convention District Regional meeting was discussed and that led the way for the Christmas Party held Dec. 15 and 16 at the Holiday Inn in Atlanta.

There was some serious celebrating going on and we heard that there was even a separate children's Christmas Party at Glenn and Elaine Summers on Dec. 16.

The January gathering was hosted by Jo, David and Rhonda Guy as well as Joey Urban of Irwinville, Ga. The highlight of the meeting was a trip to the Georgia Agrima.

In Central Florida news, the last reported meeting we heard about was on Dec. 22 at the home of Debbie Wanzie. The group gathered at the Dutch Treat Restaurant after the meeting and we heard it was a lot of fun.

Meanwhile in South Florida, the Mini-Gators met Jan. 26 at the home of Jeanne, Kathy and Linda Brown in Hallandale. We always have a great time at the Browns.

Everyone is still buzzing about the smashing Christmas Party at the Campanella (Lou, Terry, Brian, Richard, James and Daniel) in Coral Springs, Fla. Mini-Claus was on hand to give out presents as well as his new trusty sidekick and alleged cousin, Willie Claus.

Thin was in this year. Willie looks like he could have used some fattening foods to plump him up and even Santa, who in the past has been very rotund and fit for the part, must have gone on a starvation diet because right in the middle of passing out the presents, Santa's belt slipped off and he had to grab his pants right quick.

Ralph Frech and Bill Albaugh missed the package presentations. They were escorting Santa's North Pole Rent-A-Car from the top of Florida. Santa always takes precautions when there isn't any snow.

DISTRICT FIVE

(Kent.,Mich.,Ohio,Tenn.W.Va., and Ind.)

District Director Debbie Hecht reports there are 140 memberships from the "Lively 5" And Ms. Hecht has

Continued on Page 5

These happy people were part of the Regional meeting held at the Wood View Inn in West Milwaukee, Wisc. The gathering took place Oct. 19-21 with Dr. Steven Kopits as the guest speaker. Barb Yenter reports there were more than 100 people in attendance.

Matthews' to host regional

Continued from Page 4

designated the following state coordinators to see all of these members: Mary Jane Fye, Indiana; Dan Cota, Ohio; Gracie Oliver, Michigan; JoAnn Bayer, Kentucky; Debbie Robinson, Tennessee and Diana Sova, West Virginia.

Tami Herring of Ohio and Michael Robinson, also of Ohio, were named as teen correspondents.

A New Years Party was held Dec. 29 at the home of Paul and Monica Kehr with some help from Dan Cota, Karen Nadler, Mike Noller and Judy and Rich Krok.

In other District news, the Pokagon State Park outing has been delayed until March 8. Also, from the Indiana Little Hoosiers Chapter, we hear they will come out of winter hibernation in April.

There are reports that a spring regional meeting will be held in Cincinnati, Ohio. We'll have more details in future newsletters.

DISTRICT SIX
(Wisc. and Ill.)

A very special gentleman in a red suit visited the Barbara Yenter home in December and had packages for everyone. We've been told everyone really had a super time.

The Fall Regional was also quite an affair. The hostess for the affair was Judy Kaflka but she was quite busy at the hospital assisting Dr. Steven Kopits with his clinic.

The Badger Chapter raised $80 for its chapter through its raffle. Cheryl took home the winning afghan.

In other Badger news, Diane Conley has been appointed secretary-treasurer replacing Ralph Welbes who stepped down from the post. The Chapter is still seeking a vice president.

DISTRICT SEVEN
(Ark., Okla., Mo. and Kan.)

District Seven's Spring Regional will be hosted by Sanford and Mary Lou Matthews the weekend of March 22-23 at the Topeka, Kan. Holiday Inn. The rates are $28.22 for a single, $33.44 for a double and $41.80 for four people.

Dr. C.O. Leonard, a pediatrician from Johns Hopkins Hospital will be on hand and John Phipps will play for the district dance. District Seven also invites any members from around the area to also participate.

The Oklahoma City Chapter held a meeting Jan. 5 and the highlight of the meeting was a tour of the Cowboy Hall of Fame. The Gateway Chapter in St. Louis had a fine meeting at the Binkley's home.

The big District Seven Christmas Bash held in Oklahoma City attracted 18 members. If the weather had cooperated, the crowd would have been even bigger.

The Christmas gathering was hosted by the Keith McCall's with the excellent help of the Ronnie Clark family. Foy Jones was appointed as district director for the meeting. The Matthews' were not able to attend but Foy did an excellent job.

DISTRICT EIGHT
(Louisiana and Tex.)

The Hou-Gulf Chapter had its first meeting of the decade on Jan. 5 at the home of Colleen and Grady Horndt. There were 18 folks in attendance. Alida Harville's tenth birthday party was the highlight of the meeting.

Speaking of Alida, her family was scheduled to host the Feb. 2 meeting.

Continued on Page 6

LA Chapter elections held

Continued from Page 5

In the Dal-Worth area, Mary Beth has resigned as Chapter president and a replacement is being sought. Says Mary Beth, "I have enjoyed my term and regret only one thing . . . that I did not do more." The election of a new president took place in Burleson at the January meeting.

The Chapter's Christmas party was at the home of Becky Brown and her family. The annual Christmas gathering has been a longstanding tradition in the chapter.

The Dixie Lil' Highs of New Orleans, had their big holiday gathering at the home of the Alain Craccos. Several members who had undergone surgery throughout the year are just now beginning to feel in the pink again.

In San Antonio, the chapter has gained two new members and hope to get even larger in the next year.

A sad note in the district was the unexpected death of Jeff Davis of the Dalworth Chapter. He was killed in a Dec. 6 auto accident. According to District-eight officials, "He had been a member of LPA for a short time but in that time had touched a lot of lives. He will be greatly missed."

DISTRICT NINE
(Minn., Neb., N.D., S.D. and Iowa)

The Twin Cities Chapter held its holiday party in early December at the home of Kathy D'Arias in the high rise recreation room. More than 40 people attended the party which included a catered dinner and an exchange of gifts.

In other Twin Cities news, a meeting was scheduled for Feb. 23 at Fairview Hospital. There was swimming at Fairview Hospital and it was pizza after the pool dip.

On Jan. 20, there was a bowling party at the Stardust Lanes. After the keglers finished, everyone went over to president Patty Wieser's home for a snack.

There are a number of plans when the weather gets warmer including a garage sale and a May meeting workshop. Read upcoming newsletters for more details.

DISTRICT 10 and 11
(No reports available)

District Reports

DISTRICT 12
(Calif., Nev. and Hawaii)

The Los Angeles Chapter is gearing up for its National Convention in July. In the meantime, chapter elections were slated for the Jan. 19 meeting at Cerritos National Park.

The nominees included: President, Shirley Harper; Vice President, Joe Heman; Treasurer, Marilyn Hoyt and Robert Biggs and Secretary, Mary Lou Sberna.

Those nominated for the board of directors are Dorothy Henderson, Darla Heman, Shirley Rosenberg and Georgia Guild.

The Christmas banquet at the Chalon Mart attracted 82 people. It was a smashing affair.

The February General membership meeting will discuss the national convention.

Back-tracking to Christmas a little, there were a number of people who attended the Family Christmas Party.

Up north in San Francisco, there were 60 who attended the Little Little Christmas Party at the Borgwardts. The next week, the adult Christmas Party took place hosted by Jack and Ann Carlino. There were 26 folks in attendance and everyone enjoyed the meal as well as the gift exchange.

The February monthly meeting at Jon and Connie East's home in Hayward will be a pot luck affair and elections will also be held that night.

The Jan. 19 meeting was for adult LPs and Parents Auxiliary discussion group and took place in Rodeo. The regular monthly meeting was held Jan. 5.

In other district news, we were saddened to learn of the death of Brian Wanberg, who was the newly elected vice president of the Denver Chapter passed away recently following tracheotomy complications.

Also, Emory Souza of Sundland, Calif., died Jan. 6. His wife Linda died Aug. 17 and Emory leaves a five-year-old daughter, Nicole. We send our deepest sympathies and prayers to families of both these men.

Are you California Dreamin' already waiting for the National Convention? Well, to whet your appetite a little more, we present this picture of the most recent Districtt-12 members and the Los Angeles Chapter, hosts of this year's conveniion. Our last reports tell us that the temperature at the Pacifica Hottel are hovering around the 80-85 degree mark. No wonder these Californians look so darned healthy.

Lou Grant, where are you?

ED LANG
Editor

I suppose the most frequent comment I've heard since becoming editor of the Sun Reporter Newspapers is, "How's life Lou Grant?"

Being compared to Lou Grant is a compliment although our jobs really don't parallel each other. Grant, a superb actor, portrays a managing editor of a large California daily newspaper. The excitement and glitter he manages to get into week after week are but fantasy for a small newspaper editor.

Actually, crazy things do happen to each of us in the newspaper business but their frequency is far less than what is depicted on television.

The day-to-day grind is what is not shown on television. That could be because viewers would not take the time to watch Lou Grant week after week if it were.

The journalist and journalism are iconoclasts in this society. A reporter or editor is not expected to be a clock watcher. Perish the thought! While daily newspapermen up north receive huge paychecks that include overtime, small non-daily newspapermen don't receive that degree of luxury.

This doesn't mean we enjoy our job any less. On the contrary. I have never been afraid of work or time spent in a job. Actually, it has always been my philosophy to give 110 percent of my effort on the job.

The time involved in the capacity of a non-daily newspaper editor is quite extensive. We have four different newspapers a week with four different deadlines.

Monday is our South Broward County newspaper serving the cities of Hollywood and Hallandale. Our circulation is 20,000 for these publications.

Monday is what I call a semi-killer day. I arrive at 9:30 a.m. and leave about 12 hours later after all is done. Tuesday's newspaper services two large municipalities in Dade County, north of Miami with a circulation of 38,000.

Then on Wednesday and Friday, we have deadlines on our Miami Beach newspaper which have circulations of about 17,000 papers each day. The City of Miami Beach is a smaller geographical area than our other coverage areas (it is six miles east of the City of Miami with a permanent population of around 90,000 residents.

The news generated out of Miami Beach is twice as heavy and twice as controversial than in our other coverage areas. For example, for the last year, a great deal of debate has taken place over a billion dollar plan to renovate the southern tip of Miami Beach.

I am telling you all this for two reasons. First, to apologize for not putting out the number of newspapers we had last year and second, to announce that as of right now, I will not be able to serve as National Newsletter Editor after the July 1980 Convention.

During the week I usually don't get home much before 9:30 p.m. and 11 p.m. arrivals are not uncommon. So by Friday night, I am usually suffering from minor exhastion.

I've tried to keep as much of my weekend free to allow some free time with Pat and to help as much as possible with the South Florida Mini-Gators, although, my help has been minimal in recent months.

I spoke to President Gerald Rasa about the situation and his comment was quite succinct: "Your family and job come first," he said. "Then try to decide what free time there is after that."

In giving up the National Newsletter, I did ask to hold on to our People Profile series. It isn't that hard to do and I've received a lot of favorable comments about it since its inception. Plus, it spotlights members who don't usually get the recognition they deserve.

Another reason why I am attempting to cutback on my extra-curricular activities, is that Pat and I are hoping to adopt a Little Little sometime during 1980 or 1981.

The process is a long one and could require travel to another state to retrieve the child. Also, a new child requires lots of love and attention from both sets of parents which also requires time.

I thank each and every one of you for the chance to serve as editor and promise to do the best job I can for the remainder of my term.

May God bless each of you...

Burt Reynolds Dinner Theatre

1001 INDIANTOWN ROAD • JUPITER, FLORIDA 33458
TELEPHONE (305)746-5566 or (305)746-5569

January 9, 1980

Mr. Bobby VanEtten
Asst. Director
Little People of America
West Palm Beach, Florida

Dear Bobby:

I'd like to welcome the Little People of America to West Palm Beach, my home town!

I feel very close to the Little People and my good friend, Billy Barty, who visited our dinner theatre a few months ago. I am very proud of what the Little People of America stands for and I hope your Regional meeting goes very well.

Continued best wishes and much love to a wonderful group of folks!

Sincerely,

Burt Reynolds

BR:ed

Burt Reynolds sent letter
...District-4 accepted

Keith has his own business

KEITH CONNOLLEY of District-3 has his own "feed and seed" business in Delaware and we hear he is doing quite well.

The **KAY SMITH** Fund has been activated, as reported last issue and anyone wishing to help this fund should make checks payable to Johns Hopkins University designated for the Kathryn K. Smith Dwarfism Fund and mailed to Lena Lynch, c-o Moore Clinic, Johns Hopkins Hospital, Baltimore, Md.

BOB AND CONNIE RIGERT of District-2 are working hard to reactivate the Long Island Chapter. We wish them luck.

KATHY KINCHELOE of District-3 gained recognition in the annual Fall Festival in Montross, Va. She placed third in the novice division of the festival art show and also won the best decorated bicycle award.

GINNY PIMENTAL and **CHRISTOPHER SARGENT** of District One heard wedding bells on Oct. 27 becoming man and wife.

CHUCKLES PEDERSON of District-12, is temporarily in District-2 working for IBM in East Fishkill, N.Y. He is also working in the Youth Ministry at Trinity Lutheran Church in Walden, N.Y.

TONY COX of District-12, recently returned from San Juan, Puerto Rico where he was doing TV appearances on the Guiness Book of World Records show. He was interviewed by Miss Universe of 1971 and I'll bet that wasn't very hard to take.

BRIAN TEMPLETON of District-8 recently participated in the making of the movie, "Roadie". He plays a rock and roll band member.

PETE OJTOZY of District-4 recently had a feature role in a Crystal Hamburger chain commercial shown in the Southeast.

JEFF BROOKS, meanwhile, plays an elf in the new Joske's commercial seen in the Southwest. Jeff is from District-8.

PETE JOHNSTON of District-4 had a role in the new movie starring Tim Conway and Don Knotts.

BARNEY KARPFINGER of District-6 was given a testimonial dinner for his 23 years of coaching basketball at Marquette.

KIM OGREN of District-6 has left the area and has moved to Florida. Kim, where are you? We need new members down here.

ROBERT HALL of District-7 had a great send off party by Keith and DeAnna Hall. Robert is moving to Ann Arbor, Mich.

ROSCOE STIDMAN and the former **BARBARA ANN MORRIS** of District-7 became man and wife recently. Our sincere congratulations.

LOU SCHARRER, of District-4 and president of the Central Florida Mini-Gators recently took part in a research project at Johns Hopkins for the study of Osteogenesis Imperfecta.

TIM and **BARB DEATHERAGE** of District-8 have moved back into their old new home. Tim and Barb, as you may remember, lost their home to the devastating tornado in April. We're glad everything's back to normal.

CAPRICE PERRINE and **DAVID ALVARADO** of District-8 were married Dec. 8.

LPA News is published six times yearly by Little People of America, Inc. Articles and photo contributions are welcome and should be sent before the 15th of the month to Ed Lang, Editor, 3616 West Bell Drive, Davie, Florida, 33328. Photos will be returned only if accompanied by a stamped, self-addressed envelope. Send address corrections to Daniel Margulies, LPA Membership Secretary, 832 Wainwright, Benicia, Calif. 94510.

Daniel Margulies
LPA Membership Secretary
832 Wainwright
Benicia, California, 94510

First Class Mail
U.S. Postage
PAID
Miami, Fl.
Permit No. 6501

Address correction requested

First Class Mail

The Washington Post Magazine

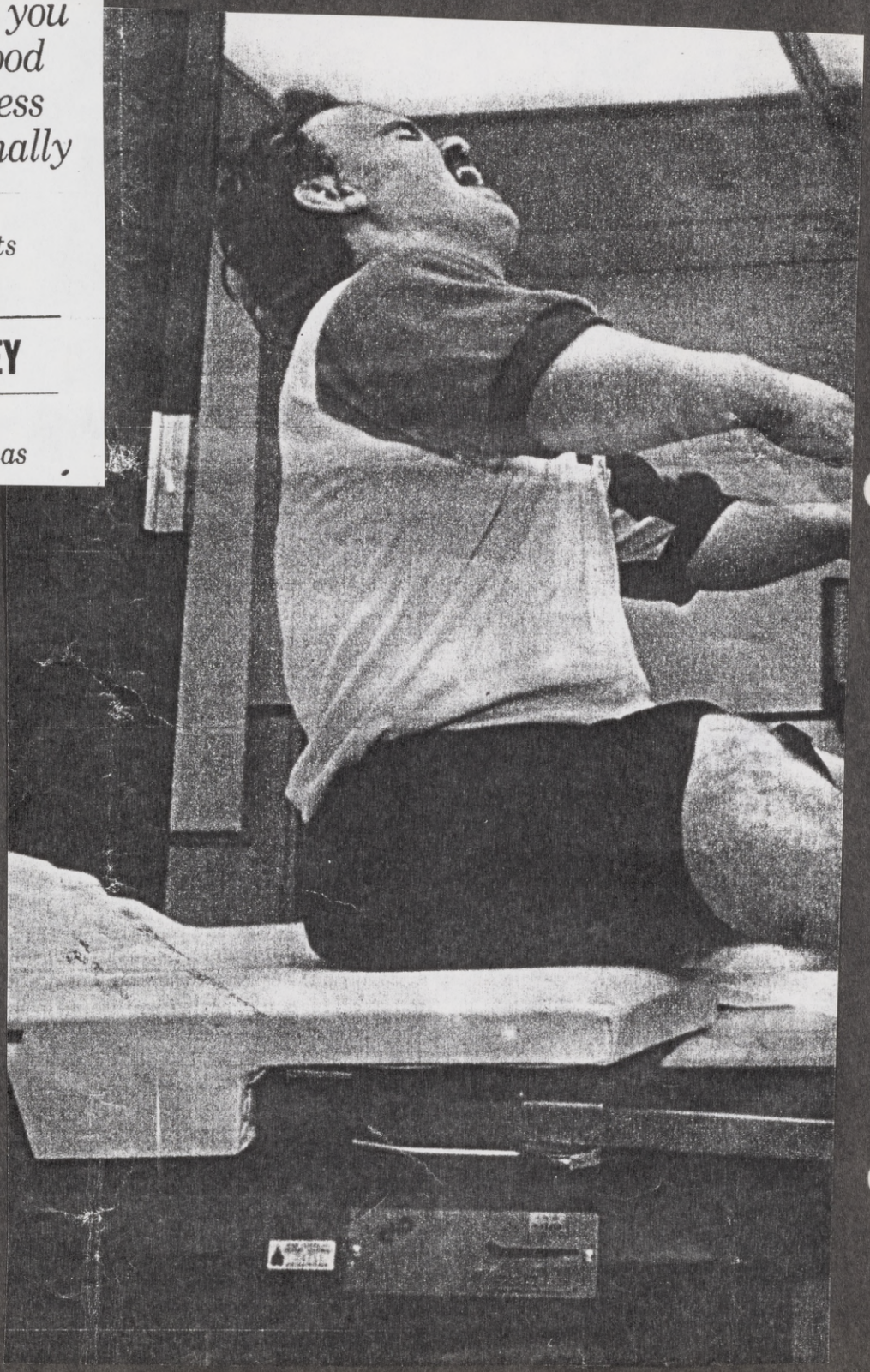
A. STICKNEY
P O BOX 633
SAN BRUNO, CAL.
94066

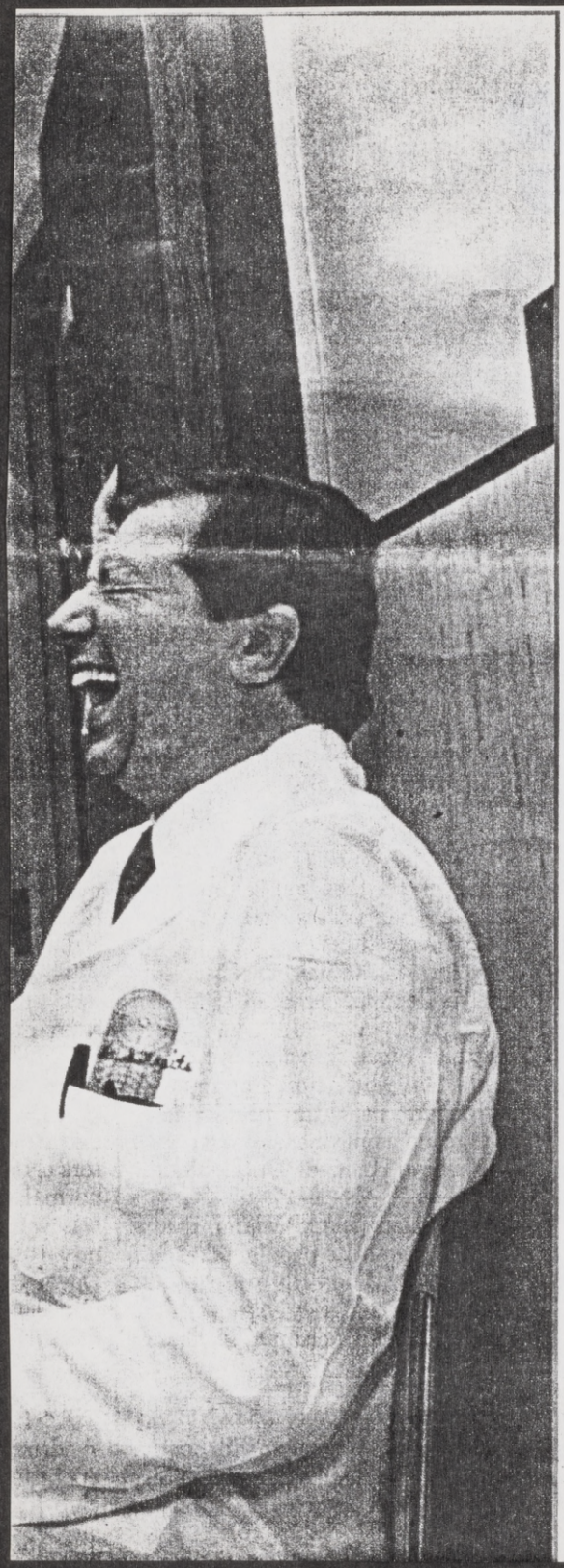
'The preached doctrine is that you cannot be a good physician if you get emotionally involved with your patients. My doctrine is that you cannot be a good physician unless you get emotionally involved.'

—Dr. Steven Kopits

BY BRAD LEMLEY

Photographs by Margaret Thomas





Dr. Steven Kopits is impressed, amazed, delighted as he walks backward down the hall, followed by the diminutive figure of 11-year-old Vincent DePaul. Sometimes a story is best told by its props, and this one is summed up in the impossibly short crutches under Vincent's arms. Vincent is a dwarf whose misaligned hips, knees and ankles have been straightened in five operations by Kopits, and now, on 22-inch crutches, he is pushing himself down the hall in Children's Hospital in Baltimore while Kopits marvels.

"Beautiful, beautiful, absolutely *korgeous*," Kopits murmurs in his soft Hungarian accent. He circles Vincent to check the leg motion from all sides. "Any pain?" Vincent shakes his head, concentrating on the 150-foot trek.

Lessons about human suffering, determination and compassion are being spelled out in neon here, but Matthew, Pierre, Wanda and the other kids in the physical therapy room are not paying much attention, nor do they need to. They are all dwarfs—or, as they prefer to be called, little people—and they have learned these lessons on their own. All have had their club feet, bowed legs, splayed hips and limp spines straightened and stiffened through Kopits' surgery, and now they are resting in their small wheelchairs awaiting their own daily physical therapy sessions.

It is a typical scene for Kopits: he is probably the only surgeon in the world who specializes in little

Brad Lemley's last piece for The Magazine was about the study of UFOs.

DR. STEVEN KOPITS, an orthopedic surgeon who works exclusively with "little people," shares a laugh with Kevin Kistler, left, at the Johns Hopkins clinic. Above, Kistler, who is 4 feet 4 inches tall and in his twenties, is measured.

people. In the last 16 years he has operated on more than 700 of them, using procedures he created himself as he ventured alone into the medical unknown of dwarfism.

It is a remarkable specialty, but Kopits is a remarkable man. He has performed grueling surgeries free for indigent clients, made 1,000-mile house calls, lodged little people in his home, financed research with his own funds, and subsisted for weeks on less than four hours of sleep nightly. He greets his child patients with a kiss, wraps his arms around crying, exhausted parents, laughs with adult patients and gets misty when toddlers emerge from casts to take their first steps.

"I love them," he says. "The preached doctrine is that you cannot be a good physician if you get emotionally involved with your patients. My doctrine is that you cannot be a good physician unless you get emotionally involved."

The love is mutual. The best evidence is Kopits' surgical schedule, booked until mid-1987. Mary Alice Johnston, 4 feet 2 inches tall, from Atlanta, Ga., whose husband and four children are also little people, says, "God made someone for everyone, and I believe He made Dr. Kopits for little people."

Xenia Palenzuela of Miami, Fla., a mother of two little people, takes it a step further: "The little people have two gods, one that they share with the rest of us, and Dr. Kopits for themselves."

ON MONDAY, clinic day, the waiting room begins to fill early. There are babies, children and young adults whose average height seems to be about 3½ feet. The contrast to Kopits, who is a full six feet tall, is striking.

The first patient is 8-year-old Nisa Ely, who has flown with her parents from Los Gatos, Calif. While she is being X-rayed, her father, Roy, tells the story:

"She was born in Columbus, Ohio, and two days after her birth the doctors came in and said the child wasn't normal, but they didn't know what was wrong with it. Then they diagnosed all sorts of things, including Down's syndrome. We spent seven months going from hospital to hospital, getting all kinds of diagnoses.

"Then we found Dr. Kopits, and he knew almost immediately what it was." It was diastrophis dysplasia, a syndrome that so far has required 10 operations, mostly to correct Nisa's club feet. She still walks stiffly, "but without Dr. Kopits, she would be in a wheelchair," her father says. "Definitely."

A VISIT TO BENJI'S WORLD: Orthopedic surgeon Dr. Steven Kopits gets down to the level of 6-year-old Benji DuGoff, one of Kopits' "little people," at the Baltimore Children's Hospital clinic. Kopits combines his surgical expertise with caring physical therapy in a technique that has won him many admirers in the medical profession. Kopits has rebuilt the bodies of more than 700 people, mostly children, affected by dwarfism.

Angered that the boy was dressing himself too slowly, the father had slapped the child, who then collapsed, a quadriplegic. Examination showed the slap had dislocated the upper vertebrae, a weak area in many dwarfs.

Other patients tell the same story: misdiagnoses and unsuccessful surgeries before finding Kopits. One boy had two failed operations on his club feet. Kopits did what he calls a "salvage job," and the boy is walking.

Meanwhile, the doctor himself has his hands full with Benji DuGoff, a tiny 6-year-old dwarf from Silver Spring. He first kisses Benji, then Benji's younger sister and finally his mother, then lifts the squirming boy out of his wheeled walker. Benji attacks Kopits with Batman and Robin dolls. Kopits retaliates with a frontal tickling attack.

Preliminaries over, Kopits uses a hinged protractor to measure the angles of Benji's limbs. The child's back is deeply swayed, and his legs join his hips at 85 degrees—a fixed sitting posture. His arms are short and tend to fold in toward the chest, and a thumb is permanently swung away from a palm in the hitchhiker's position typical of the syndrome. He chatters throughout the examination; in response to direct questions he says, "Guess," and looks inscrutable.

Benji has had one operation to mend his club feet; today's checkup helps Kopits plot when further surgeries will be needed. Ninety percent of his patients are younger than 18, and he has developed a formula to establish surgical "windows"—times in a dwarf child's life when operations will yield the greatest long-term benefit. It is a subtle art with many variables: age, condition, life style, family support.

"The history of orthopedic surgery and dwarfism has been to respond to crisis," Kopits says. "My main contribution is to establish the goal of planned management—to correct the problem before it becomes catastrophic."

Outside, Mary Alice Johnston is waiting with her daughter, Bunny, 15. Bunny will have surgery tomorrow to remove steel hip-straightening plates called splines, and to have a wedge of pelvic bone inserted below the knee to solve a wobbling problem that causes her to fall frequently.

This waiting room is familiar territory to Johnston. Through the years she has periodically loaded her car with one, two or all four of her children and driven here from their home in Atlanta. Once, three of them had major surgeries and had to be taken home in double leg casts. "We had a van then. I just threw them in and drove the whole bunch home nonstop, since I couldn't have gotten them out anyway."

She leans back in her chair. "We're people, too. We go through a lot. You get the stares, the whispering, and then you've got the physical aspect to deal with too.

"A lot of doctors give you these vibes like they're thinking you can't have serious problems, you're just sort of cute. It makes you want to bop 'em where it hurts, you know?

"But Dr. Kopits, he's my buddy. I love him. I told him one time, 'I'm going to try to get Heidi and Trent [9 and 8 years old, respectively] to do what you do. Why not? They could build a platform for them around the operating table." She laughs.

The day wears on. Kopits' nurse-practitioner, Diane Davis, orders lunch for him in the hospital cafeteria, but he never gets it. At 9 p.m. he is still here, examining a tiny blond boy from Annapolis whose legs bow out like a croquet wicket.

PEOPLE WHO HAVE short-stature syndromes divide into two broad categories: those whose limbs and torso are proportional, commonly known as midgets, who lack growth hormones; and those whose limbs are short, known as dwarfs, whose condition is genetic. (Both types prefer to be called little people.)

Because proportional short-stature syndromes usually do not cause orthopedic problems, Kopits works exclusively with dwarfs. Dwarfism occurs in about 1 in 10,000 births—there are an estimated 20,000 dwarfs in the United States, well over a million in the world.

Enduring the rude stares and just getting by in a world that is largely out of reach would seem to be burden enough, but the real trial of dwarfism is dysplasia: the abnormal alignment of bones and muscles that causes pain, crippling and even death. Achondroplasia, the most common type of dwarfism, is characterized by spinal problems and bowed legs; spondyloepiphyseal dysplasia congenita causes hip disease, creates foot deformities and produces a small chest that squeezes internal organs; diastrophic dysplasia, perhaps the most severe syndrome, can cause cleft palate, hand deformities, curvature of the spine, hip and knee problems and club feet. Kopits has worked with 32 syndromes, each with its own problems.

"My major motivation for working with dwarfs is not that they are dwarfs," he says. "I work with them because they are a disabled population that was not being helped."

Still, after 16 years of close association, he now appreciates the mystery of little people that has fascinated mankind for thousands of years. "They are an old race. This is one of the deep things I have learned. They feel a tremendous kinship. Watch a dwarf child, born to average-sized parents, when they bring him into the waiting room here. If there are other little people in the room, he is instantly drawn to them, like a magnet. I have seen this happen so many times."

LISTEN CLOSELY to Kopits' accent and you will hear more than Hungarian: there is a trilled Spanish "r" and traces of French and German. "At various times, I have spoken five languages fluently. I had to."

Fleeing the closing vise of invading Soviet and Nazi forces, his family left Budapest in 1945, when he was 9 years old. They were intercepted and detained in an S.S. concentration camp, but bribed their way out. "It is amazing what a bottle of cognac will accomplish in wartime," he says.

Kopits' father, an orthopedic surgeon, took the family to Austria, France and then Spain.

Kopits says his father wanted to take the family from Spain to America, "because it was the best place for a doctor to go," but in 1948, "the Hungarian quota was so small that it appeared he could not get in for several more years so he decided to accept the first invitation he got, which was from a friend of his who was a professor of orthopedics in Argentina."

The son stayed 16 years and received his medical degree in Argentina. "I was raised to respond to disability. My father was one of the pioneers in treating people who had osteogenesis imperfecta—the 'pretzel people.' We had the crippled beggars of Barcelona and Buenos Aires eating at our table all the time. They were the people you would see pushing themselves along the streets on platforms. Some had brilliant minds, brilliant, and were reduced to begging. These were my father's friends. When he retired, after practicing medicine for 60 years in eight countries in five languages, he said the most important lesson he had learned was to love his patients."

In Buenos Aires Kopits married fellow Hungarian expatriot Edina Schmidt, and in 1964 the family, with three small children, came to Baltimore. In 1968 he became chief of pediatric orthopedics at Johns Hopkins University Hospital.

In January of that year, a man brought his 3-year-old dwarf son to the hospital's emergency room. Angered that the boy was dressing himself too slowly, the father had slapped the child, who then collapsed, a quadriplegic. Examination showed the slap had dislocated the upper vertebrae, a weak area in many dwarfs. Kopits fused the neck and the child slowly recovered.

His interest in dwarfism piqued, Kopits dropped by a convention of the Little People of America, a self-help organization that happened to meet that year in Baltimore.

"There I saw a scene, it is still vivid to me: 25, maybe more, little people, taking turns riding in a wheelchair, dragging themselves with crutches and limping canes. It was very sad, very moving."

He began to accept more dwarf patients, and his reputation among them grew. He also surveyed the medical literature on dwarfism. It did not take long. "There was nothing, really. Some isolated case studies."

By 1975, 80 percent of his patients were dwarfs. In 1978, he left his post as chief of pediatric orthopedics to work with little people exclusively at both Johns Hopkins and nearby Children's Hospital. Since then he has assembled an intensely loyal staff who seem to have two goals: supporting Kopits' efforts, and keeping him from killing himself with overwork.

"We worry that he will drag himself down until he is unable to function," says Peggy Albert, who oversees the Little People's Research Fund, a nonprofit entity set up to support Kopits' work. "Not long ago he finally took a sabbatical, and he was like a little kid. It was the first time in 10 years he had seen the changing of the seasons. He spends so many 14-hour days in here he had forgotten what it was like."

Kopits' long days in the hospital, blending one into the other, have meant sacrifices for his family. "It's routine for him to come home after everyone has gone to bed and leave before anyone gets up," says his son Steven, 23. He remembers a night when his father wearily stumbled into a family birthday party. There was a cake that read, "Happy Birthday to You." Everyone sang, but Kopits was so tired that he could only remember the birthday song by reading the words in the icing on the cake. As the words were cut out, piece by piece, he had to stop singing. "It's par for the course," the son says. "It was never a question of getting used to it, since it was always like that."

Through it all, Edina Kopits has learned that a surgeon's wife needs a sense of humor: "After all these years, if he were home more, I wouldn't know what to do with him."

The Kopitses have three children; none have chosen medical careers. Helen, 25, is in a graduate program at the University of Maryland architecture school; Steven, 23, is in graduate school studying business at Loyola University in Baltimore; and Laszlo, 19, is a sophomore at Haverford College in Pennsylvania.

The Kopits family has forsaken much of the wealth that a specialist can generate. Kopits' salary as an associate professor at Johns Hopkins is much more money than most people earn, but it is much less than what he could earn in private practice—as much as $500,000 a year, he says—but he seems not to care. "I am totally oblivious to money," he says.

With a two-and-a-half year waiting list for surgery, Kopits has been criticized for not disseminating his special knowledge of orthopedics. He is sensitive to the criticism, but says there is only so much he can do, and he is concentrating on finding help. He is pushing for approval to build a dwarfism research center on the Children's Hospital grounds, where he can train other orthopedic surgeons. He is also spending every spare moment writing a diagnostic and surgical guide to the major dwarfism syndromes. Medical artist David Jonah has worked on the illustrations for five years, laboriously building anatomical models by tracing photos of a CAT scanner's X-ray "slices" onto thin clay sheets, then cutting out the flat clay shapes and stacking them into representations of bones and muscles. "It's not easy, but it's the only way to do it," says Jonah with a shrug. "Thanks to Dr. Kopits' success, there are no cadavers available."

Kopits' technique has won admirers. Says Dr. Robert Robinson, former chief of orthopedics at Johns Hopkins, 'These problems he is solving are very difficult. These are not routine hip and knee replacements. He practically has to invent a new operation for each individual. He's one of the best around.'

"What would you say if I told you that through this whole thing, I have felt that I was taken by the hand. Each time a new challenge has come to me, something has happened to prepare me for it.

"Example: One time, a veterinarian asked me to help him to operate on a dog, who had the same problem with the neck as certain types of dwarfism. So we cut the arch of C-1 [the upper vertebra], the arch pulled away from the spinal cord and the dog died, respiratory arrest.

"Now it is a week later. I am operating on a boy from Quebec, and the exact same thing happens—I cut the arch of C-1, it begins to pull away from the spinal cord, and the anesthesiologist tells me the boy is going into respiratory arrest.

"But this time, I am ready. I grab the arch of C-1, pull it back, the patient recovers . . . and the operation goes well."

"I have done very, very many of those operations, and the same complication never happened before or since. Imagine if the order of the operations had been changed, if I had operated on the dog a week *later*.

"This kind of thing keeps happening—I am prepared just in time. So I really feel like I get some special help—there is a determinism about the whole thing. If you can say nothing else about me, you can say that I am a man who is sure he is doing exactly what he was meant to do."

BACK IN THE hallway outside the physical therapy room, 13-year-old Wanda Murray is using a walker to retrace the route Vincent just completed. Kopits is impressed, amazed, delighted all over again.

"Look at these," he says, pulling out two photographs. They show Wanda crouched like a baseball catcher. "When she first came here, she was folded up and locked like this. Because of her inactivity, her bones were so soft you could scoop them out with a spoon . . . This one was a good candidate for dying."

Kopits has lost only one patient on the operating table, from complications with anesthesia. The inserting of a respiratory tube in little people can be a problem, though Kopits says technology has developed so that it would not happen now. Kopits does not like to talk about such matters.

Across the linoleum floor, Wanda is making steady progress. Although her back still has a pronounced curve, her hips and legs are straight. Kopits waits for her.

"When I get to you, I get a kiss?"

"Yes, you do," he says. When she reaches him, he delivers the promised prize. Then he carries her back to her little wheelchair.

"Do you want to hear my song?" Kopits agrees, Wanda presses a button on her cassette player, and soon the physical therapy wing is filled with "You Decorated My Life" by Kenny Rogers. Kopits listens with a faint smile, and a dozen others in the big room stop their knee flexes and parallel-bar walks to watch and listen.

Anywhere else it would be a hopelessly maudlin scene: a schmaltzy song, a tiny, doe-eyed girl and the obsessively dedicated surgeon who helped her walk again. But here in Kopits' world, where bones are chiseled, mothers are kissed, crutches are tiny, and love and pain are too clear to be denied, it seems entirely appropriate. ■

TUESDAY IS surgery day. Bunny is wheeled into the bright, tiled operating room. She is breathing nitrous oxide and oxygen, and her eyes are taped shut. Her legs are washed with yellow soap and propped up with folded surgical sheets, forming a reclining "U" shape.

"We will double-team this one," Kopits says, his eyes smiling above the mask. He and Dr. Mark Koris, a first-year resident, sit on opposite sides of the table. Kopits draws a purple line across the right hip and down the thigh, then slices through the skin, fat and muscle, while Koris does the same on the left. Within 25 minutes both hips are opened, revealing the five-inch splines, each held in place with two screws.

Until now, Kopits has been humming Mouret's "Rondeau" and joking with the scrub nurse and anesthesiologist. But he discovers the plates are stuck—three years of calcification have welded them to the bone.

Now comes the nitty-gritty of orthopedic surgery—essentially, carpentry practiced on human beings. Kopits and Koris sweat and grunt as they twist out the imbedded screws, then they use hammers and chisels to pry the plates loose. Before the operation is over they will have used pliers, vise-grips, files, drills and saws. In some cases, the tools are identical to those on a home workbench.

After one particularly energetic session of sawing, Kopits looks up, and his eyes smile above his face mask. "Delicate surgery," he says.

But at times it is delicate, extremely so. After taking a wedge of bone from the pelvis, he opens the lower knee and the wedge is inserted. "There is a place here, behind the knee, where the artery trifurcates—splits into three. If it is severed, the leg is usually lost." He then deftly drills a hole a few millimeters away, and screws down a T-shaped plate over the transplanted bone.

Kopits' salary as an associate professor at Johns Hopkins is much more money than most people earn, but it is much less than what he could earn in private practice—as much as $500,000 a year. He says, 'I am totally oblivious to money.'

Kopits' technique has won admirers. "He is an absolutely excellent surgeon," says Dr. Robert Robinson, former chief of orthopedics at Johns Hopkins. "These problems he is solving are very difficult, lots of tough calculations. These are not routine hip and knee replacements. He practically has to invent a new operation for each individual. He's one of the best around."

It is not merely good technique that makes Kopits different. More revealing is that he tries to make his surgery as kind as possible. He will sew up his incisions with so-called "plastic" closures, a meticulous method using tiny stitches in the manner of plastic surgeons. The method avoids the more common "train tracks" often associated with major surgery. "I like to do this, especially for the girls," Kopits says. "If a lover runs his hand across it in the night, he feels nothing."

INTERSPERSED with the marathon days and white nights are lighter moments. Kopits' first emergency house call on a little person involved landing in a two-seat airplane in an Arkansas cow pasture. On another occasion, he fashioned a neck brace from aluminum siding for a child in Akron. The local hospital had no braces that would fit someone so small.

His awareness of disability was raised in Detroit, where he once spent a weekend in the home of a dwarf couple. "They had scaled down everything. When you have to duck down to shave, reach down for the light switch, the bed is two feet too short and the john is one foot off the floor, you learn how disability can be created by disproportionate environment. It made me think: You know, if you went to a planet where there were only little people, they would look at you and say, 'Hmmm. Isn't he a tad long?'"

Albert tells the story of the 1982 Little People's convention in Reno, Nev., where Kopits was playfully ambushed in his hotel room by 15 little people who wore surgical masks and gowns. "They plastered him—put him in a cast from his armpits to waist and around both legs. They were all over him three deep. It was like Gulliver and the Lilliputians. He loved it."

Kopits goes to the conventions every year and examines little people 14 hours a day for the entire five days. When he sees them assembled for a speech, the scene is a striking contrast from the one he saw in 1968: "There I see, all together, maybe 700 little people, and I have treated maybe 200 of them. The treated ones compare themselves to the untreated ones, and the difference is obvious. It is very satisfying."

AT 10 P.M. Kopits has just finished 10 straight hours of surgery. He has plopped down into a wheelchair (there are wheelchairs everywhere at the hospital) and is in a reflective mood.

JOHNS HOPKINS HOSPITAL
BALTIMORE, MD. 21205

STEVEN E. KOPITS, M.D.
Pediatric Orthopaedic Surgery

To Our Friends, Supporters, Patients, and Their Families,

PROGRESS REPORT, 1981

This past year marked a milestone of progress in our work for the Little People. The Little People's Research Fund became a working reality. This organization, started by a group of friends in 1980 with the sole purpose of securing financial support for my work with the Little People, was finally incorporated in November of 1980 as a nonprofit, tax-exempt organization. By May of 1981, in recognition of the importance of this work, the Board of Trustees of the Children's Hospital and Center for Reconstructive Surgery granted free office space and other essential support to the Little People's Research Fund, Inc. (LPRF). Peggy Albert, Coordinating Secretary of the LPRF, started working at the Children's Hospital on June 15, 1981.

The purposes of the Little People's Research Fund are:

1.) To support the research into the orthopaedic disabilities of the Little People, in order to improve methods of treatment and prevention of disabling complications;

2.) To provide financial assistance toward travel and medical expenses for families and individuals who cannot afford it;

3.) To provide support for the education and training of other physicians and allied personnel by: a.) seeking continued financial support for our textbook on "The Orthopaedic Management of Dwarfism"; and b.) by establishing a training fellowship in the orthopaedic surgery of dwarfism under my direction at the Johns Hopkins University.

The Little People's Research Fund has the enthusiastic support of dynamic people and the prospects of success in reaching the above goals are excellent. At present, we have not broken through the day to day struggle to cope with expenses. In addition to the salary of Peggy Albert, the LPRF has taken over the support of my research assistant, Sandy Tutles, and of the medical artist illustrating our book, David Jonah. In addition it is administering funds received for specific purposes, such as the medical care of patients in financial need and those earmarked for a large computerized study on Achondroplasia.

Our work has received considerable recognition locally, nationally and internationally during this past year. Toward the end of 1980, the first newspaper report which gave an account of our work was syndicated by The Associated Press to 200 newspapers across the country. Through an 8 minute segment of the syndicated TV program, "PM Magazine", an estimated 50 million viewers were informed about this work taking place in Baltimore. This was shown nationwide 3 or 4 times during the early months of 1981. You can hardly imagine the tremendous response in the form of inquiries by potential patients, many of whom had previously given up all hope for improvement. Many of them heard of the Little People of America for the first time. Some now have the benefit of treatment.

In the spring, we were on the Luther Starns radio show with Pat Hurley, one of the directors of the LPRF, and Bobby Van Etten, President of the LPA.

A newspaper article by Geri Kobren appeared in the Sunday supplement of the SunPapers in Baltimore on September 20, 1981, and had a very significant local impact. I enclose a copy for your information.

On November 27th, Robin Zeltner, Bobby Van Etten and I were guests on a local TV show, "People Are Talking" which was aired in Washington and Baltimore.

Through all of this publicity, we are trying to inform the public about the lives and some of the problems encountered by Little People, and that their physical disabilities need not be a barrier to the achievement of an independent lifestyle. In many cases, treatment and prevention of the disabling deformities is now possible. Most of our results justify our optimism in this regard and we have made major advances in the past year in several areas.

Achondroplasia: You may recall my letter of November, 1980 about our study of Achondroplasia, the largest entity of dwarfism. Since then we have seen many patients on the verge of paralysis. These are usually young people in their 20's and 30's who, over a period of weeks develop weakness and numbness of their lower extremities, lack of control of the bladder. Although we know that this occurs because of a narrow spinal canal, we still don't understand why other Achondroplasts with equally narrow spinal canals don't experience the same complication. You may recall that years ago we started a prospective study measuring all possible parameters hoping that a statistical evaluation would give us the answers which are not obvious by deductive thinking. Two students have worked the past two summers, organizing and programming a large amount of data concerning patients' histories, clinical and neurological examinations, and x-ray findings. To date, we have 360 out of 850 examinations on the computer with approximately 57,000 bits of information. I have spent over 2,500 hours on this study over the past six years. Added to this are 1,100 hours of the students' time and you can easily figure out the magnitude of this effort and the costs involved. All of this effort is however justified when one

considers the many young people who, in the most active years of their lives, are stricken by paralysis. Dr. George Udvarhelyi, Professor of Neurosurgery at Hopkins, has made significant progress in the neurosurgical treatment of the patients who have come to a near-paralysis state, yet our understanding as far as the mechanics involved in reaching that state will only be improved by the completion of this study. The information derived will prove essential for the care of Little People with Achondroplasia.

Diastrophic Dysplasia: Major advances in surgical care were made in diastrophic dysplasia which, although about 10 times less frequent than Achondroplasia, has an even greater incidence of disability. In a recent study of our nearly 50 cases, we have established that only one-third of diastrophic Little People are able to walk functionally after the age of 12. The remainder are confined to wheelchairs or crutches. We have finally begun to understand the complex nature of the leg deformities which cause their inability to walk after the age of 7 or 8 years.

Furthermore, we have come to understand the nature of the clubfoot deformity in diastrophic dwarfism, the treatment of which has defied orthopaedic surgeons all over the world and has led to so much frustration that current textbooks of orthopaedic surgery advise not to treat the diastrophic clubfoot deformity. We have encouraging results with our treatment at this time.

Others: Additional advances were made in Pseudoachondroplasia, the Kniest syndrome, and the syndromes of Spondyloepiphyseal Dysplasia.

Besides Dr. Udvarhelyi and myself, other members of the full-time staff at Johns Hopkins are gaining significant experience within the fields of their specific expertise with Little People. Dr. Vernon Tolo, Director of Pediatric Orthopaedics and Chief of the Spinal Service, has been gaining experience in the treatment of severe spinal deformities in conditions of dwarfism. Dr. Andrew Brooker, Associate Professor of Orthopaedic Surgery at Hopkins, has been performing total hip joint replacements for Little People.

We attended the LPA Convention in St. Paul, Minnesota in July, 1981. In addition we held regional clinics in West Palm Beach in February, Denver in June, Peoria in October, and Dallas in December. We attended all these clinics with Diane Davis, R.N., P.N.P., and Miss M. Hank, R.P.T. (Many of you who went through rehabilitation with Miss Hank will like to know that she married Mr. Ed Doerr on January 19, 1982).

Internationally, I lectured at the Quadrennial Meeting of the International Society of Orthopaedics and Traumatology in Rio de Janiero in early September and subsequently was invited to Sao Paulo, Brazil for several lectures. The first addressed a group of about 60 parents who gathered in response to an ad in the papers, and who had never heard anyone speak about dwarfism before. These were parents of children with dwarfism who considered themselves unique, since most of them had never encountered another couple with the same problems. They had kept all the heartbreaking problems to themselves. This was their first opportunity to hear

about other Little People, specifically stores of success about our Little People of America, and about the hopes of treatment. At the end of a long sharing session, they decided to organize a mutual help society, like the LPA. At this point, the "Gente Pequenha" (Little People of Brazil) is a thriving reality and they are sending a delegate to the International Meeting of the LPA to be held in Washington, D.C. this April. Their orthopaedist will be my first trainee.

In November, I lectured to the British Skeletal Dysplasia Society in Liverpool, England and at the Department of Orthopaedics of the University of Alicante in Spain. While there, I visited with the family of Andres Lopez-Pasqual, whom many of you know. In late November, I was guest lecturer to the Venezuelan Society of Orthopaedics and Traumatology in the city of Merida, high up in the Andes.

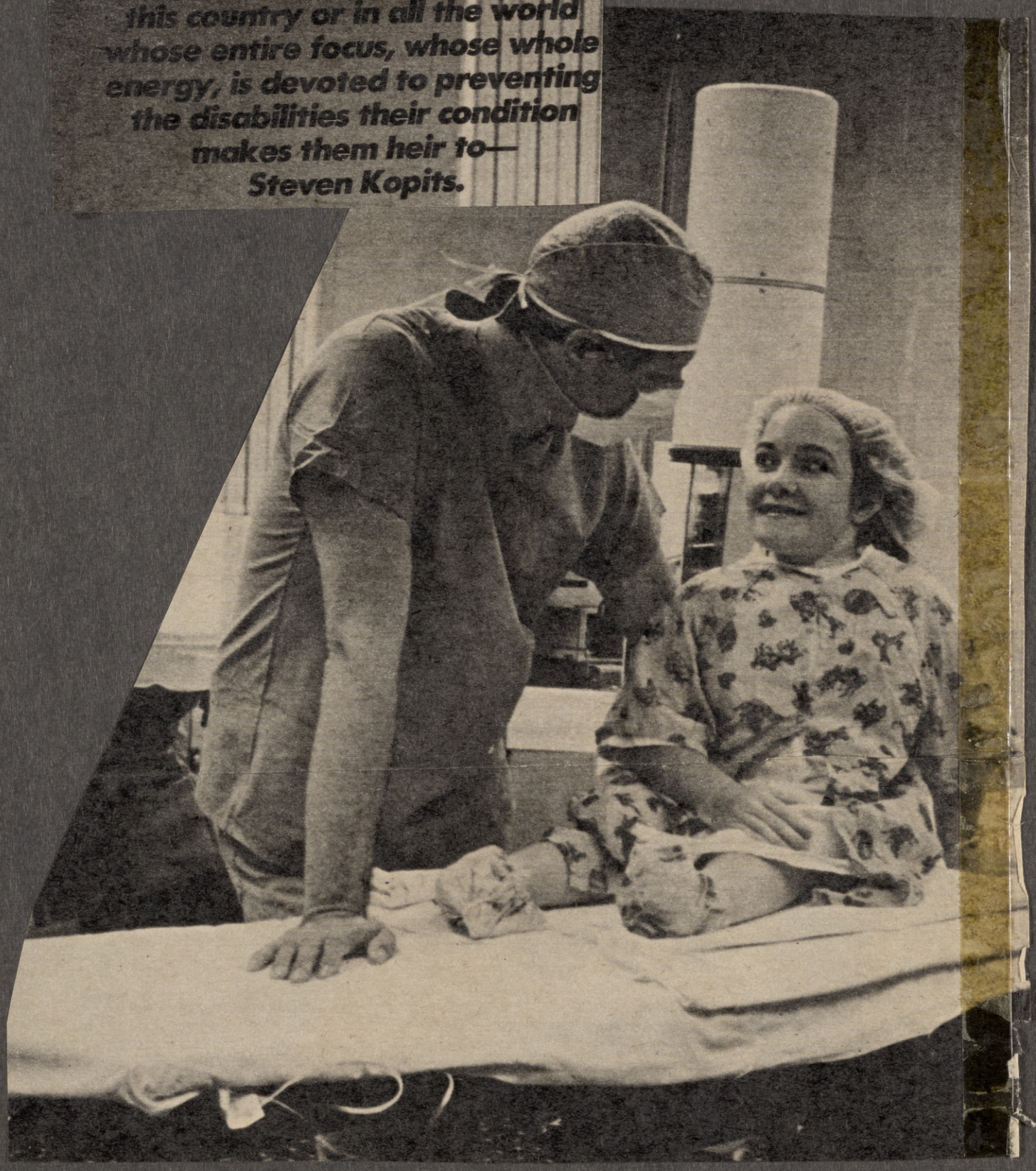
I hope you've found this lengthy report interesting. I thank you for your support over the years, which has kept this effort going. We count on your continued support and help to carry on our work.

With the best wishes for 1982, I remain yours with best regards and my gratitude,

Steven E. Kopits, M.D.

March, 1982

They have brought their orthopedic problems to the man they believe is the only one in this country or in all the world whose entire focus, whose whole energy, is devoted to preventing the disabilities their condition makes them heir to—
Steven Kopits.



Dr. Kopits chats with Ellen Highland before surgery.

Dr. Kopits and Mildred Hank, associate director of physical therapy, check Kathy Penland's progress.

By GERRI KOBREN
Photos by ELLIS J. MALASHUK

With three children in the hospital, all of them in leg casts, all of them slated for long recuperations, extensive physical therapy and maybe repeated surgery, Mary Alice Johnston's teariness is understandable.

Mrs. Johnston and her husband have had a rough time of late. Residents of Atlanta, they couldn't find anyone in Georgia who could correct the hip deformities that had their 12-year-old stumbling about, or the bowed legs that kept her out of fashion boots and augured knee problems later on for her and her bowlegged younger brothers.

So they brought the children to Baltimore, and Pete Johnston used up his vacation time to stay with them. When he had to go back to work, his wife stayed on alone. She would have to get the youngsters home eventually, with their legs still spread-eagled in plaster; would have to care for them in that immobilized state, and then would have to bring them back to Baltimore to get the casts taken off and the therapy started.

Mrs. Johnston is sitting in a waiting room at Children's Hospital, and she is brushing big tears off her face as she talks. In the chair she ap-

"I have one [child] whose parents refused the surgery. The child sits like a pretzel. Her spine is so deformed she bends over double. Her neck is dislocated. She is panting for air. I have known her since she was 2. Do you know how that hurts me?"

A family conference with Dr. Kopits: Mr. and Mrs. G. Randles with Timothy, 4, and Bryan, 7.

pears to be of normal height, but her feet do not come anywhere near reaching the floor, her arms are unusually short and her head is disproportionately large.

She isn't crying about her own abnormalities, or about her children's, or about the continuing personal strain, or the obvious hardships.

She's crying out of love for and gratitude to their doctor. "I wrote him a card, and I told him he was God's gift to the little people," she says. "The Lord provides someone for everyone. Till Dr. Kopits, there's never been anyone for us."

Mary Alice and Pete Johnston are achondroplastic dwarves. So are three of their children. A fourth, adopted, is a pituitary dwarf. Like others of abnormally short stature they prefer to be called "little people."

And like hundreds of other little people from all over the country and around the world, they have brought their orthopedic problems to the man they believe is the only one in this country or in all the world whose entire focus, whose whole energy, is devoted to preventing the disabilities their condition makes them heir to—Steven Kopits.

There is no accurate census of the population of little people in the United States; the most frequently cited estimate puts their number at about 20,000. Of these, some 8,000 are achondroplasts, whose short limbs and bowed legs are modest problems next to the twisted legs and curved spines and vertebral dislocations that lead to crippling, paralysis and early death for those who suffer from some of the 33 other dwarfing conditions now known.

ORTHOPEDISTS other than Dr. Kopits operate on little people, and it is possible that if the Johnstons had looked hard enough and far enough, they might have found some help for their children elsewhere. But it is also unlikely that any other physician could have proceeded from the experience gained in

years of practice with the dwarves.

Dr. Kopits has performed more than 1,000 operations on 700 little people over the past 10 years. At the Hopkins and at Children's Hospital, it is widely held that no one else anywhere can approach that record. He is often asked to speak at medical meetings; he thinks he is invited to give the sessions an exotic touch, because afterwards he stands around waiting for questions and comments that seldom come. Few of his colleagues seem to have any involvement in the problems of the little people.

They are his life's work, his calling, even his avocation. Salaried by the Hopkins, he makes no money from the fees charged for his services; yet he works nights and weekends, scrambling to treat his patients and at the same time to write a textbook on their orthopedic problems. When he is not away at little people's conventions or running out-of-town clinic sessions sponsored by little people's families, he is performing surgery, in three or four long sessions each week.

"On Mondays I am operating," he says, "so on Sundays I am in the hospital talking to parents. Saturdays I make rounds. In other times I am working with my research assistant, with my illustrator, with the young men who are doing the statistical analyses on the computer."

"He has no hobbies," says his wife Edwina. "His only hobby is his work. He lives, breathes, and I think he'd die too, for his work."

—o—

Steven Kopits does not at first seem like a man obsessed. He is tall, over 6 feet, well built, just this side of husky. His smile lights up his face. He speaks with a trace of a foreign accent, and punctuates with his hands and body. Genial and dramatic, he leans forward to whisper, jumps up to mimic, laughs, mourns, tells stories—and always about his dwarves.

He was born in Budapest, Hungary, in 1936, the son and grandson of orthopedic surgeons. At 9, with the war ending and Europe on the brink of its East-West split, the family escaped; captured by the SS, they escaped again and moved on through Austria, France and Spain. When the doors of immigration to the United States proved inpenetrable, they went to Argentina. Steven Kopits went to medical school there, and made it into this country with a surgical internship at Union Memorial Hospital in 1964, and an orthopedic residency at the Hopkins from 1965 to 1968.

For the next 10 years he headed the pediatric orthopedics service at the Hopkins. In 1978 he resigned to devote himself utterly to the little people.

He makes house calls for them all over the country, using kitchen tables to adjust slipping casts, flying out and landing on makeshift runways when emergencies arise in the South or Midwest, buggy-riding into Amish country to visit patients there.

Little people from far away have been known to stay in the Kopits home while they're being evaluated in Baltimore. When he's in their part of the country he stays with them. Once the tall doctor was the house guest of a married couple who had had their furnishings scaled to their own height. He had to bend from the waist to shave at their bathroom mirror, stoop to reach a light switch, line up chairs to accommodate his length in the bed in their guest room.

"It was *beautiful!*" he says. "It gave me an idea of what they have to go through."

HIS DAUGHTER is an architect; his sons have said they do not want careers in medicine. Unlike their father, they want to spend more time with their families.

Mrs. Kopits is planning to open a downtown shop to sell South American imports. She finds work for herself, she says, so she will not get pulled into his obsession.

And yet she understands, because how can one get to know the little people, Mrs. Kopits asks, and recognize the grimness of their future and the promise of their treatment, and not support this lonely effort to help?

Her husband talks in generalities about his introduction to the little people at the Moore Clinic for the study of medical genetics at the Johns Hopkins Hospital. Mrs. Kopits recalls a specific incident that triggered his interest:

An averaged-sized man had brought his child into the hospital. "He was a lovely little boy, 4 years old. He had been slow getting dressed and the father had slapped him across the face. The boy collapsed and lost consciousness."

The child's parents had apparently not realized he was a dwarf—some conditions are so subtle they are not immediately diagnosed—and even if they had known, they would probably not have understood the instability in their son's cervical vertebrae that led to his collapse.

High in the neck in some of the little people, the round bones dislocate, or slip out of the vertical alignment, so that they pinch the spinal cord and impede breathing. The process progresses with age, and dwarves are known to die in young adulthood when the nerves that control respiration are compressed to the point of complete respiratory shutdown.

The vertebrae can also be dislocated by a blow to the head, a snap or twist of the neck.

And so this little 4-year-old passed out from a smack on the face. And Steven Kopits, seeing the child and recognizing the problem, moved into a field that had been barely charted before he came.

—o—

The progression of the little people's problems can be as insidious as cancer. Each of the dwarfing conditions has its own deformities, many of which do not show up at first. "But the seeds of trouble can be present for 10 years before the clinical appearance," Dr. Kopits says, "and then they lead to catastrophic disabilities. By their teens, some of the children go to the wheelchair, or they die. So I have to reconstruct everything preventively. I take the child at 3 or 4, and start the work."

Even though a youngster may be without obvious disabilities, the parents will agree to the surgery. "I spend three hours examining the child," Dr. Kopits explains. "Then I tell the parents, 'Your child is getting weaker. The scoliosis is progressing. The hips are dislocating. The knees are going bad. The child may die. He will need 90 or 100 hours of surgery.' Can you imagine what that is like for the parent? It can blow your mind. So I have to do it in such a way that it doesn't; I have to surround it with hope, cushion it with hope. I show them pictures, so they can look at the outcomes. I have parents in the hospital meet other parents, to compare notes. I say, 'Your child is really worse than you thought, but there is treatment. It is sort of terrible, but others have had it and the outcomes will be good.' "

Among the less common dwarf syndromes is one Dr. Kopits and his associates call the Struwick, after a patient who died of it. Kathy Penland, 19, of North Carolina, is such a dwarf. Aside from her short stature, her first symptom of disability was a weakness in one arm and leg, for which the doctors at home could find no cause. Her parents brought her to Dr. Kopits in 1974.

"Kathy," Dr. Kopits remembers, "was getting paralyzed from the neck down. Her hips were a shambles. Her knees, spine, ankles . . . each one added to the problems of the others."

With index finger and thumb of one hand, he makes a circle. Inside, he slips the plastic stirrer from a cup of coffee. The circled finger and thumb of the other hand go on top, then slide forward and down. The plastic—Kathy's spinal cord—begins to bend. Clearly the fingers—her vertebrae—need to be braced so they will stand firmly in line.

"I was able to fuse her neck. Then I did her hips, which were almost at the point of no return; she will still probably need total hip replacements in the future."

He shudders and leans his head on his fist. "I have 52 patients like Kathy, of all ages. And I have one whose parents refused the surgery. The child sits like a pretzel. Her spine is so deformed she bends over double. Her neck is dislocated. She is panting for air. I have known her since she was 2. Do you know how that hurts me?"

—o—

The exact point at which an operative procedure arises is often impossible to

Dr. Kopits about to put a cast on 8-year-old Matthew Doering.

date. Dr. Kopits denies that he is a surgical revolutionary. His major contribution, he says, is "planned management," and this arises from the opportunity he has created for himself to see and treat hundreds of little people at various stages of health and disability, and thus predict the progression of their problems.

No one seems to have done that before. Studies of little people's pathology were under way when he became interested in their orthopedic abnormalities, but treatment, he says, was given only in crisis situations; surgery was performed after the disabilities were manifest.

"I suppose I should have been scared to death to try anything new," he admits. "But I really never gave it a second thought. I was using basic orthopedic principles proven by time. I always felt so right about it. I saw the alternative to the surgery, and it was so dismal, so absolutely horrible, that I knew I must move."

He was not always successful.

THERE IS one dwarf syndrome—the Morquio—that he describes as especially terrible. "Morquio children are born to normal parents, and appear normal at first themselves. But at 3 the knees start to go bad. The chest humps. The growth rate plateaus, and then stops entirely at 3½ feet, when the child is 8. In the early grades, Morquios go to school normally, but at 6 or 7, there's a big change. They stop walking. The doctors used to try to fix their legs, but it wouldn't work because the problem that seemed to be in the knees was a red herring. The real trouble is in the neck. Eventually they die of paralysis of the respiratory muscles, men in their 20s, and women in their 30s. This can now be prevented."

Dr. Kopits treated his first Morquio in 1969, fusing the cervical vertebrae of a 3-year-old. "I was just a novice then, and I didn't know Morquios' necks didn't fuse in the normal way. In fact, I have found that many of the operative procedures that work with normals do not work in the little people, and have to be adjusted."

When the boy was 14, the neck fusion was attempted again, and this time seemed to succeed. But there had been damage to the breathing apparatus in the interim, and Dr. Kopits's voice drops to a grieving whisper as he recounts the rest of the story.

"The boy said he wanted to spend Christmas with his family in a mountain cabin near El Paso, Texas. Christmas day the medical examiner called to tell me my patient had died."

He flew out west to participate in the autopsy. The youngster, he found, had had shortness of breath his first night on the mountain, and had been blue from lack of oxygen by the time his parents brought him down the next day. "From that and other observations I learned that once the respiratory center has been damaged, it will not respond when challenged by altitude, by certain diseases or under anesthesia. Now we know we must be careful. We put the patients in the intensive care unit for pneumonia, and keep them there longer after surgery."

Other surprises have more satisfactory endings. Patients who undergo neck surgery often require "halo casts," circular metal devices that are screwed into the outer layer of bony skull and then attached with rods to a body cast; this arrangement keeps the head immobile as the bones heal and harden.

LITTLE PEOPLE, he discovered the first time he tried to put the screws in, do not have the double layer of skull normals do. "This is not written in the textbooks," he notes. "Can you imagine my feelings when I realize I've gone through the skull?"

But the cast has to go on, so he proceeds carefully. The screws are not set all the way in, and after the patient has gone home to recuperate, they sometimes come loose, allowing the halo to slip. "You can't leave the patient that way, and you can't ask anyone local to fix it, " he says. "You have to go where the patient is."

The first out-of-town emergency was in 1972, in Marshall, Ark. "The child's mother called me at my office at the Hopkins at 9:30 in the morning, and said the pins were falling out. I told her, 'Wrap the head in a towel; I'm coming.'"

The only plane that would get him anywhere near Marshall that day was the 11:30 a.m. flight to Memphis, leaving from National Airport in Washington.

"I packed my tools in my VW, drove down the expressway like a bat in hell, and was clocked at the exit by a state trooper. I told him I was a doctor making a house call in Arkansas."

At Dr. Kopits's pleading, the skeptical

rooper called a police official on whose hild the doctor had operated. The official ouched for Dr. Kopits, and the trooper ed him, with siren screaming, down Washington's congested Constitution avenue, and even parked the car for him at he airport.

"The plane was almost empty, so the tewardesses put me in first class and lied me with mai-tais. This was a good hing, because when we landed in Memphis a big burly guy met me and said he was going to take me on to Marshall in his wo-seat Piper. The door on the passenger ide didn't close. I had to hold it the whole way. Without those drinks I would have ied of fright."

AND THEN, suddenly, he continues, the pilot dropped through the clouds, announced he was going to and in a cow pasture, and buzzed the razing creatures till they got out of the way.

The child's father was waiting with a ar, and took him home. "I discovered," he ays, laughing now, "that the best lit place n any American house is the kitchen, and he best place in a kitchen is the table. I ave worked on patients on kitchen tables n Albany, Phoenix, St. Louis, Akron, and Orlando."

On occasion, when the casts could not e reset at home, he's had to carry his little patients into small-town emergency rooms. "In most cases," he's found, "hospital personnel are very kind. You say you are from that place called 'the Hopkins,' and it opens many doors."

—o—

Diane Davis was a general duty nurse at the Hopkins, working on the pediatric orthopedics floor, when she first met Dr. Kopits. Drawn in like so many others, she started talking to him about the possiblity of joining him in his work. The parents of one of Dr. Kopits's patients, grateful for what he had done for their child, picked up the tab for Ms. Davis's extra training as a nurse practitioner.

She takes some of the pressure off him and the patients by counseling, educating, acting as go-between, doing pre-admission interviews, making travel and overnight arrangements for them and their families. Patients who fly in from out of town have to fly out again, often in casts that keep their legs spread and prevent their sitting up. They may need four seats on a plane, a van to take them to the airport and another to take them home, a reclining wheelchair, and someone to talk to when they get low, or scared, or don't know how to manage.

Ms. Davis travels with the doctor from the Hopkins, where he takes patients who need the 8- or 12- or 14-hour operations, to Children's Hospital, where he operates on those needing shorter procedures, and where he sends all of them for physical therapy.

And while she works long, hard hours, she watches him and knows that what she can do is not enough. "I see the wear and tear on him," she says. "He bears the brunt of the responsibility. He goes into surgery, and each time he sweats . . . he almost sweats blood. And when he comes out 12 or 14 hours later, he's drained."

AT CHILDREN'S Hospital, Mildred Hank, a physical therapist, has worked with Dr. Kopits to develop techniques for getting the little people ambulatory again after their drastic surgeries and long immobilizations. Most of them, no matter where their home towns are, will have to stay for an extended period at the hospital, or return daily as outpatients.

So what Ms. Hanks can do isn't enough either.

"Many patients come in from foreign countries," Dr. Kopits says. "and they do not have medical insurance. There's a Morquio man right now in the Dominican Republic; to take care of him would cost $50,000. He is probably going to die. There's a child in Hungary with 90-degree scoliosis. . . . I have about six people who could be helped, who cannot be helped, because of money. I could donate my services, I have donated my services—but the hospitals still have to be paid."

There are insured Americans who also cannot be helped because they live too far away, and they cannot afford the coast-to-coast air fares or the long disruptions for convalescence and physical therapy in Baltimore.

And even though dwarves in remote places are beginning to hear of Dr. Kopits through their contact with each other, or, as recently happened, through a WJZ "Evening Magazine" segment that was telecast on other Group W stations across the country, there are still some who are not helped because they don't know help is available.

So even what Dr. Kopits can do is not enough.

The book is his own cushion of hope. He hasn't got all the data he needs for it, but he's close, he says; he likens what he's doing to completing a jigsaw puzzle. "You start with the blue pieces, and then you put together the green pieces, and you do all this with great difficulty. And then all of a sudden, it explodes! It multiplies! You begin to fill in the gaps."

He stands now at the brink of what he calls "a historic moment," the point at which the knowledge is about to be disseminated so patients need not travel away from home to find their help. "I don't think another doctor will get to see 700 dwarves in his lifetime," says Dr. Kopits, "but he will be able to look at the book and say: 'Kopits did this, but now I have a better idea!' "

Nurse Diane Davis holds Jennifer Dowd, 8, as Dr. Kopits talks with William Dowd.

A group of supporters also launched the Little People's Research Fund, headquartered at Baltimore's St. Joseph Hospital. Says Peggy Albert, the research fund's executive director: "Every week I get calls from desperate parents with horror stories about what's happening to their children. A mother from Georgia called recently—she has an 8-year-old dwarf daughter—and told me that their doctor was trying to cure the child's bowed legs by having them broken and reset each year. It's tragic how much ignorance remains on this subject."

Two basic conditions cause dwarfism. So-called pituitary dwarfs lack growth hormones, and they remain tiny. In the past, these well-proportioned but short-statured persons were known as "midgets," but this term is now regarded as insulting. Growth hormones have helped eliminate much pituitary dwarfism.

The most common cause of dwarfism is genetic mutations that cause bones to form and grow improperly, resulting in disproportionate bodies. There are more than 80 different syndromes responsible for these bone dysplasias. The condition is often accompanied by severe bowing of the legs, hip problems, clubfeet and problems with the heart, spine and respiratory system. These so-called genetic dwarfs are the focus of Dr. Kopits' work. Their parents tend to be of normal size, incidentally.

At 8 a.m. on a recent Monday, I watch Kopits operate on Stephen Hatch, 15, who lives in American Fork, near Provo, Utah. Stephen has pseudo-achondroplasia. His head and torso are normally proportioned but his legs are stunted and bowed and his arms are short.

"When Stephen was 11, we took him to a Little People's convention in Reno and met Dr. Kopits," says his mother, Beth Hatch. "We watched a girl who was as straight as a stick and was actually dancing. Dr. Kopits said the girl had been like Stephen before he had operated on her."

Kopits had realigned Stephen's hips two weeks earlier. The next task was to straighten his legs. This Monday, the goal is to straighten Stephen's right leg, which takes eight hours. Before setting the hips and legs in a new plaster cast, Kopits invites me to examine the two legs. The right one is now discernibly straighter—and also about three inches longer.

The next day's schedule has Dr. Kopits booked to see patients from Maryland, Texas, Alabama, West Germany and Israel. Pat Hutson, who has traveled from Bonn, West Germany, with her daughter, says of Kopits: "He's our child's link to a more hopeful world. He will give her a future."

Gordon and Virginia Hendrickson of Rochester, N.Y., have brought their 16-year-old daughter Sheri to Baltimore to see Kopits.

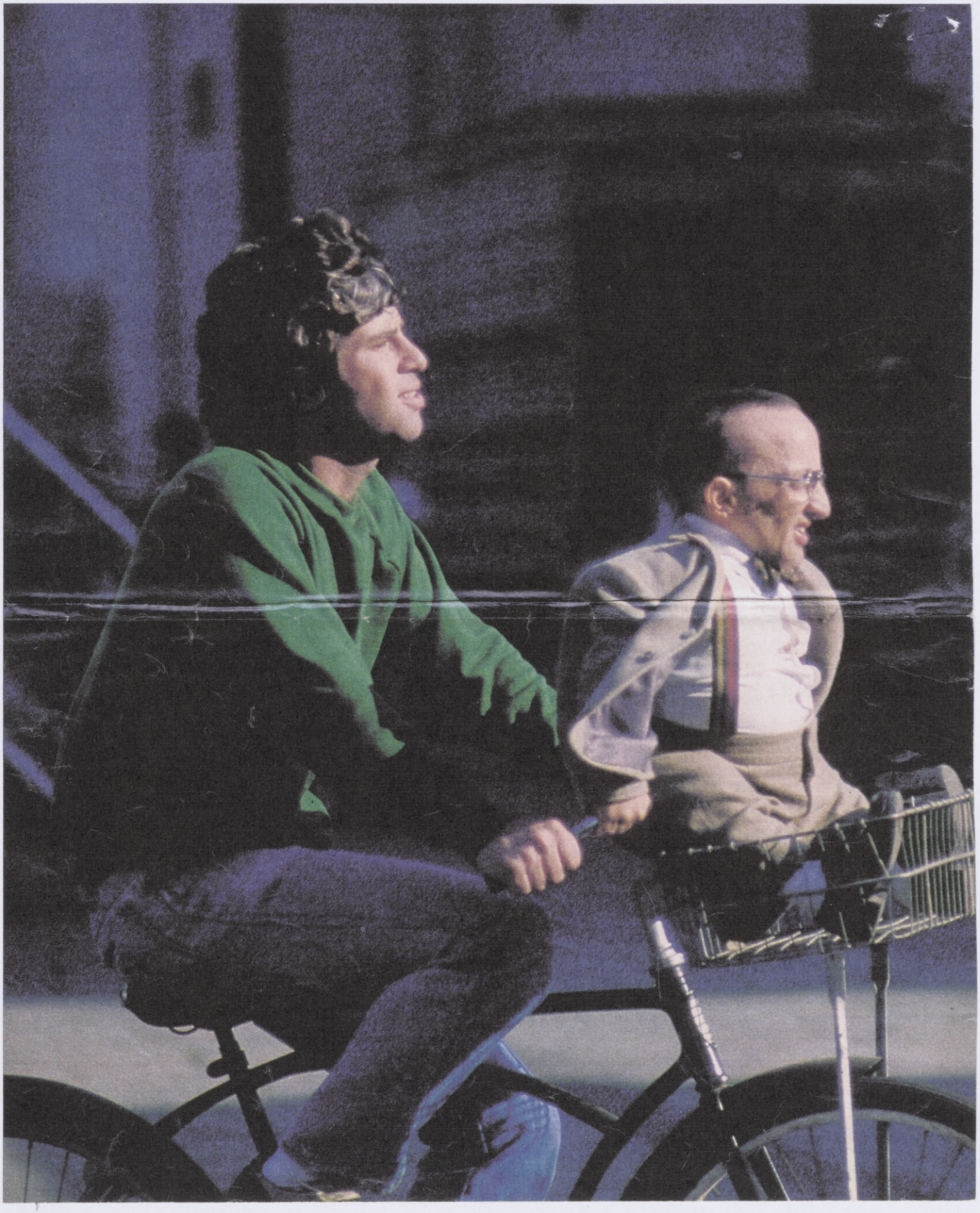
"She's been examined by six specialists," explains Mrs. Hendrickson. "They're baffled. They don't know what to do, and they can't help Sheri. She's been taking 10 codeines a day for the pain, and the pills aren't helping. We heard about Dr. Kopits, and we felt this was our only chance."

After a lengthy examination of the girl, Kopits is clearly touched. Her pains, he explains, are probably not orthopedic in origin but may be related to her dwarfism.

"I'm just a poor orthopedist from East Baltimore," Kopits says with a wry smile, "but I want you to know that I care about you, and I'm going to do everything in my power to help you get well." He then gives the Hendricksons his home telephone number, tells them to call if there are any problems overnight and arranges to have their daughter admitted to the hospital for tests. As the family leaves his office, Kopits bends his lanky frame down, hugs his new patient and kisses her on the cheek. She is clearly smitten.

Kopits watches the family leave and shakes his head. "Six doctors, and none could help her," he observes. "It's tragic really. All the time, I see the desperation of good physicians who can't do anything for these patients. That is what keeps me going."

For more information, write to: Peggy Albert, Little People's Research Fund, St. Joseph Hospital, Dept. P, 80 Sister Pierre Drive, Towson, Md. 21204.



LITTLE PEOPLE IN THE BIG WORLD

Hollywood recruits 150 for a new comedy about the Munchkins

When Tinseltown repeats itself, what starts out as pure fantasy may wind up as farce. For a few brief weeks in 1938 Hollywood swarmed with droves of dwarfs—or little people, as they prefer to be called—on hand to play Munchkins in the classic *Wizard of Oz*. But while Judy Garland was piping "Over the Rainbow" into a sound-stage mike, much the most entertaining action in town was off camera. Old-timers still chuckle about the wild all-night parties the transient little people threw at the Hotel Culver, where MGM had put them all up. It could have been a movie all by itself, and come summer it will be. Scheduled for release in late July, *Under the Rainbow* is a zany spy spoof starring Chevy Chase as a secret agent who stumbles into Munchkin-rife Hollywood in 1938 and winds up chasing a murderous Nazi spy. Casting called for 150 Munchkins not more than 4 feet 6 inches high, and little people came from all over the U.S.—one of them a veteran of the original Munchkin troupe. For Pat Bilon *(left)*, 34 inches tall, Hollywood was definitely the good life, a chauffeur and everything. Instead of the Hotel Culver, this time the little people were housed at the Pacifica. The partying was as raucous as ever.

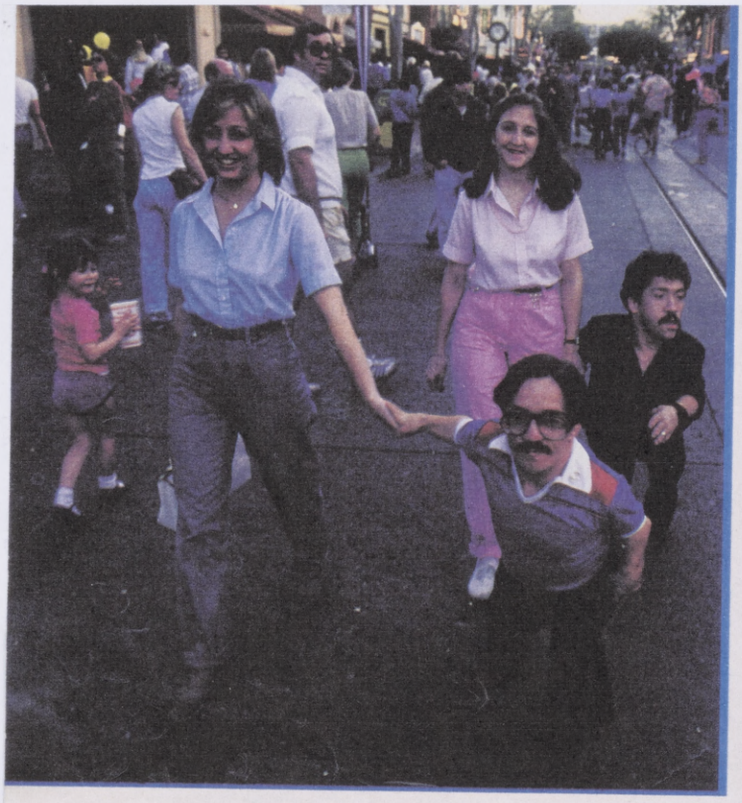
Pat Bilon gets a lift across the movie lot from production assistant Jim Petti.

Photography: Gregory Heisler
Reporting: Nancy Griffin

A WIDENING WORLD OF OPPORTUNITIES

The $100 a day paid to Munchkin extras is good money by any standard, but other opportunities for the estimated 100,000 little people in the U.S. have begun to expand well beyond circuses and sideshows. Among those who answered the casting call (acting credits not required) were a diamond broker, a real estate agent, a dental technician and a bank officer. "People don't just look at us and think 'freak' anymore," says veteran actor Billy Barty, who plays the Nazi spy in *Under the Rainbow*. Twenty-four years ago Barty founded Little People of America (LPA motto: Think Big), which claims a membership of 5,000 today. Whatever the strength in numbers, for those more accustomed to being the only little person for miles around, the convocation in Hollywood was sometimes upsetting. "It's a shocking experience—like meeting your clone," remarked one extra. Others expressed concern that the film would contribute to the stereotype of little people as hellions and wise guys. Said Pam Ybarra, a movie production assistant who doubled as a Munchkin: "It's true we like to party, but that's only one side of it."

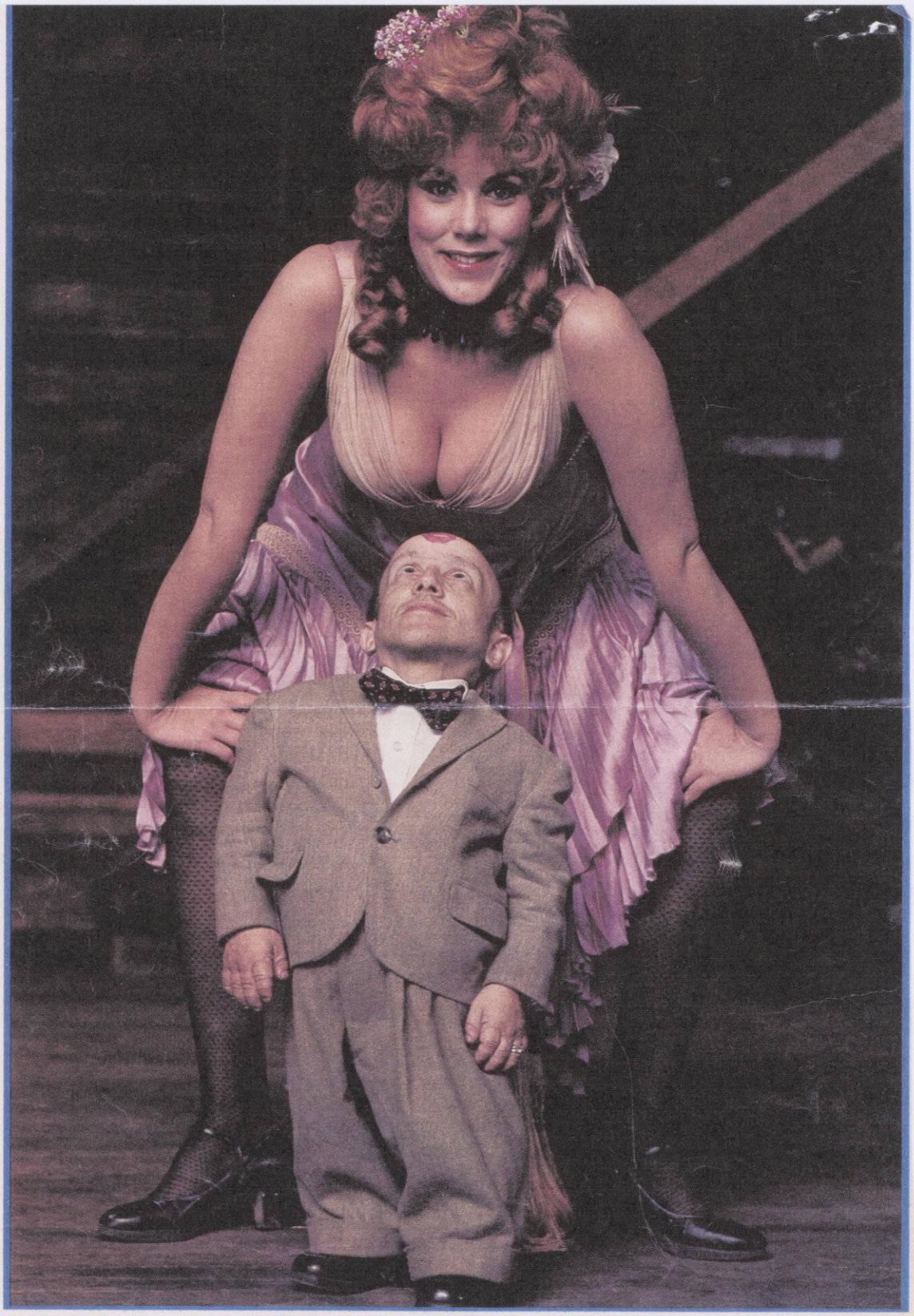
In a scene from the movie, a towering house detective (Pat McCormick) is swept along in a tide of angry Munchkins. Below, Chris Romano (left) and a bewigged Michael Gilden take a break during filming.



SIZE PROVES NO IMPEDIMENT TO LOVE

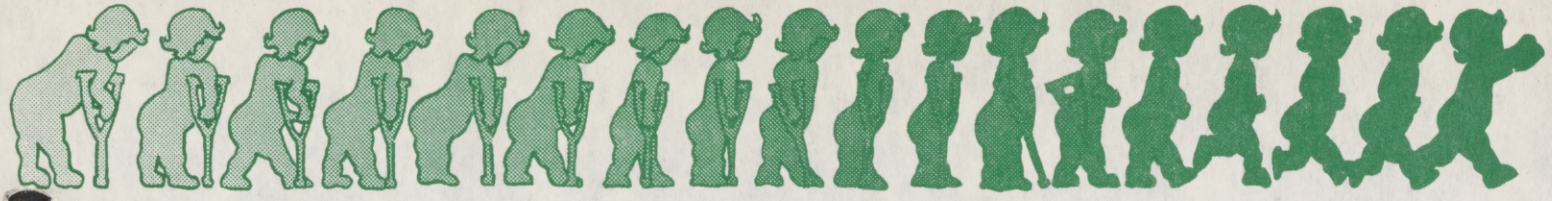
First cast as mere Munchkin extras, brothers Sal and Phil Fondacaro showed such extraordinary talent that director Steve Rash found himself adding new scenes just for them. Sal, 28, is a musician. Unsolicited, he wrote a song that the producers are considering for the movie theme. Phil, 22, graduates from Cal Arts this month. Both 43 inches tall, the brothers are married to women of normal height, who are sisters. Sal and Karen met as students at California's Fullerton College. They introduced Phil to Karen's sister Jeanine, and the two couples were married within three months of each other in 1978. Unlike some types of dwarfism, the Fondacaros' condition arises from a recessive rather than a dominant gene, which minimizes the likelihood that either brother could sire a dwarf. Phil and Jeanine have already produced two bouncingly normal babies. Sons of a Fresno physical therapist, the brothers have long since resigned themselves to gawking adults and giggling children. It's when wisecracks are directed at his wife that Sal sees red. "I've had to drag him away by the back of his shirt," Karen says, and chuckles. "At work, the word among the guys is that anyone who flirts with me will get his kneecaps broken." Nor is Phil one to grin and bear discrimination meekly: "I screamed so much about not being able to reach the elevator buttons at school that they lowered all of them," he says. "Next I'm tackling public telephones."

During a break in shooting, the Fondacaro brothers Sal (above, foreground) and Phil tour Disneyland with their wives, Karen and Jeanine. At right, Phil hugs two-and-a-half-year-old son Andrew, while Jeanine plays with baby Nicholas on the Corona del Mar beach.



NO DREAM IS TOO BIG

A whiff of Hollywood filled more than a few little extras with dreams of silver-screen glory. At least 10 opted to stay on in Los Angeles. For Pat Bilon it was enough to savor the memory of Bridget McNamara, a studio hairstylist who landed a bit part herself as a dance-hall extra. Producers dubbed Bilon the next Yoda (after the gnome in *The Empire Strikes Back*), but Pat walked away from it all, returning happily to Youngstown, Ohio, where he works as a radio dispatcher in the sheriff's office. ♠



LITTLE PEOPLE'S RESEARCH FUND, INCORPORATED
The Children's Hospital Inc. and Center For Reconstructive Surgery
3825 Greenspring Avenue - Baltimore, Maryland 21211 - Tel. (301) 383-0022

March, 1982

Dear Mrs. Hughes:

Isn't it discouraging to think how few of the people around us know anything about dwarfism beyond the obvious shortness of stature? So few realize that many are affected by progressive deformities and have the need for surgery during the growing years to keep functional. Even the medical profession is largely ignorant of both the problems and the possibilities of treatment. In our efforts to gain knowledge about the causes of disability in the different conditions of dwarfism, searching for better methods of treatment and prevention, we have been financially dependent on you and you alone. Those of you who know the problems also know the importance of what we are trying to develop: functional individuals who will lead an independent lifestyle; who can choose to go to college rather than to confinement and isolation; who can, with proper treatment, look forward to a normal lifespan rather than paralysis or early death, as is often the case without treatment. This work of research and development costs money, a lot of money. We have been asking, and you have been giving; this is how we have made it this far.

A group of friends, seeing my concern and dismay over the lack of funds, organized the Little People's Research Fund, Inc. to provide continuous support for our work. I hope you like the logo on our letterhead as it expresses what we stand for: function and vitality. The Little People's Research Fund is your organization. It assures a continued medical and research effort, and it will be here when we are gone. Its service is to the Little People, those who have been neglected for so long and whose time has finally come.

Even though we are optimistic about major grant funding in the future, we are battling day to day expenses at this time. We need your tax-deductible contributions more than ever to continue our work. As you realize, we can only ask those few, like yourself, who understand the problems, and the goals we want to reach for the Little People. If you have not given recently, we appeal to your generosity for a tax-deductible contribution to the Little People's Research Fund, Inc. Please be our partners in this work. You will receive periodic progress reports and, in the near future, our first brochure, hot off the press.

Many thanks in advance, and best regards, Yours in friendship

Steven E. Kopits, M.D.

Little People conventioneers give themselves a cheer i

The Little People stand table-tall at Reno convention

RENO, Nev. (AP) — Engineers, actors, attorneys and hundreds of others who stand no higher than a hotel reception desk gathered here to celebrate the 25th year of an organization that teaches little people they too can think big.

Harrah's hotel-casino built a platform at one craps table. And, so the 650 people who came from all over the nation to the Little People of America convention could reach the elevator buttons, the hotel provided rubber-tipped wands.

There was dancing for teen-agers, softball, a basketball game and time for sightseeing at the anniversary meeting this week. And there were workshops on genetics, jobs, schools and clothing.

"The purpose of the organization is to let little people and their parents come to grips with their short stature," said Lee Kitchens, a 52-year-old engineering manager with Texas Instruments in Lubbock, Texas, and a past president of the Little People of America.

He said that by helping them accept themselves as they are, the organization seeks to let little people "move out into society and become productive, useful citizens."

A quarter of a century ago, dwarfs were rejected by public schools and opportunities for jobs outside circuses were limited.

Today they are doctors and lawyers and members of other professions, but they are still struggling to be accepted by "average" people — a word they prefer to "normal."

"Short stature does not automatically mean that we are short on brain power," Kitchens said. "It's a genetic snafu. It's no different from red hair or blue eyes."

The organization was born in Reno, the invention of actor Billy Barty, and began with about 20 members. It now has more than 3,000.

"The most significant thing that a little person has to do is to be able to accept himself for his own net worth and to consider in context the statements and comments made by others," Kitchen said.

"Most of the comments you get right now as you walk down the street are from children, who are very honest; old people who are uninhibited; and the stupid and insensitive," Kitchens said.

Harrah's sought to avoid being insensitive. The hotel-casino installed ramps to the registration desk and lowered shower heads. Bob Martin, the vice president and general manager, said, "We're keeping an eye on the incidental things, like providing stools in the casino area whenever needed."

Members of the Little People come from all ethnic backgrounds and range in age from babies to people in their 70s. All are under 4-foot-10. Barty is 3-foot-9, Kitchens is 4-foot-1.

Proportioned dwarfs, incorrectly called midgets, usually are victims of malfunctioning pituitary glands, said Dr. Clair Francomano, a Johns Hopkins Hospital medical resident training in genetics. Most disproportioned dwarfs, who have short limbs but average-sized trunks, have achondroplasia, a failure of cartilage to form properly.

A score of medical specialists are here to counsel the little people and to study them. A medical advisory board hopes to develop centers in various parts of the country to treat little people.

"If we can make the general public aware that little people are no different from anyone else, in their wants and their hopes and their desires . . ." Kitchens said, "we will have overcome most barriers — barriers actually in the observer."

A scene from 'Little People'

Dwarf Pride And Hurray for It

JOHN HAS A problem. Everyone wants to pick him up.

You may be tempted to do so yourself when you see him tonight on a lovely little program titled "Little People." If you're looking for some temporary relief from the Olympic Games, try it and meet a group of very interesting human beings. There will be times when you will want to cheer (10 p.m., Channel 9, with a reshowing Saturday at 9:30 p.m. on Channel 32).

They used to be organized under the banner of an organization called Midgets of America in a day when "dwarf" was a word no one wanted to use. Their new name is Little People of America and the change of name as well as attitude is a story that is told with both good humor and sensitivity by filmmakers Jan Krawits and Thomas Ott for PBS.

AS THE PROGRAM shows, "little people" can be born to conventional parents and can also, in turn, produce conventional children. But fortunately this program is not focused on the medical end of the subject, so stick with it and I believe you will be rewarded with some observations that can enrich us all.

The program opens on a riverboat excursion of the Little People of America with dance bands, picnics and laughter. Most of the hour is made up of interviews with some remarkably attractive people who tell us about the lighter, more affectionate aspects of their lives — their surprise when they discovered they were different from the other kids, their efforts to succeed in a world of larger people, and their delight in finding there are others like them.

"When I met the others for the first time, I was overwhelmed to find how nice it is to have eye-to-eye contact with people," says one chap.

There is a talented comedian-philosopher on this program. The producers fail to identify him — and shame on them, because he's the star of "Little People." For the purposes of this review I will call him John. He has some wonderful moments describing the problems of living in a world designed for bigger people:

"One day I looked at the bathroom in our house and said to myself, 'God, we can't use it!' After washing my hands, I reach up for a towel and the water runs down my arms. So we solved it by raising the floor two feet. Now, when the big people say something is wrong with me because I can't use their bathrooms, I tell them to come to MY house and use MY bathroom and they'll discover that something is wrong with THEM!"

John has devised something he calls Dwarf Pride. "People may say that it's foolish to be proud of being a dwarf but it's more foolish to be ashamed of it."

He enjoys his interaction with other minorities — especially blacks. "They say that for 200 years their people were sold as slaves. S - - -! For 5000 years my people were given away as gifts!"

THROUGHOUT literature dwarfs have been pictured as either super-evil as some kind of monsters or super-good as in "Snow White and the Seven Dwarfs." John sees all this as part of their heritage and believes they should be proud of it. He carries his philosophy of Dwarf Pride one step further than the black counterpart when he adds:

"If you feel pride in yourself and you feel pride in your people, it's almost impossible not to make the next step, which is to feel pride in ALL people."

There is a lot of good common sense in this neat little program every viewer of every minority can relate to.

"If we're the ugly people, society needs us because without the ugly people there can be no Beautiful People. Even if that's the way society chooses to see us, we're still needed as part of the whole. So let's give each one of us the opportunity to play a significant role in that society."

Solving big problems for little people

It's been about 20 years since Johns Hopkins geneticist Victor A. McKusick, MD, first addressed an organization known as the Little People of America (LPA) on dwarfism. McKusick's delineation of an autosomal recessive form of short-limbed dwarfism known as cartilage-hair hypoplasia among the Amish population had recently been publicized, and members of LPA were interested in learning about the causes of their short stature.

At the time, most physicians knew little about dwarfism. People with short limbs were considered to have achondroplasia; those with trunk abnormalities were thought to suffer from Morquio's syndrome.

McKusick's initial contact with the national self-help organization formed by short people led to a remarkable, ongoing cooperative effort between the LPA and Johns Hopkins University School of Medicine, Baltimore. As a result, a comprehensive research program sprang up at Hopkins that so far has led to the identification of nearly 100 distinct, heritable genetic conditions that produce dwarfism. Innovative treatments and counseling have followed nosology and description, although McKusick says the ability to "find out about these defects at the gene level and develop ways to correct them" still lies in the future.

Accurately estimating the prevalence of short stature is not easy. McKusick believes several million people in the world may be affected by conditions stemming from nutritional deficiency, psychosocial causes ("failure to thrive"), pituitary deficiency, skeletal dysplasias, various inherited biochemical defects, and unknown causes. In this country, about 10,000 children may suffer from hypopituitary dwarfism caused by failure to produce human growth hormone. Perhaps another 35,000 or more have what is termed disproportionate short stature, in which the limbs or the trunk are shortened. This condition is thought to affect one in 8,000 live-born children in the United States, often appearing as a new mutation.

The Hopkins program deals with all forms of short stature, offering growth hormone treatment to those for whom it is appropriate and conducting research on growth hormone deficiency. However, unlike many other programs on growth disorders, it also emphasizes the diagnosis and management of the skeletal dysplasias, the basic biochemical causes of which are unknown and for which no methods of increasing height are available.

Unlike persons with proportionate short stature (midgets), many with skeletal dysplasias face crippling changes, paralysis, or even death if orthopedic and other abnormalities are left untreated. At Hopkins, McKusick has succeeded in marshaling the skills of many specialists to develop ways of alleviating or correcting those deformities and other problems, often with strikingly successful results.

And, as patients have flocked to Baltimore from all over the country and abroad, "the program just grew like Topsy," says McKusick, who headed it until becoming chair of the Department of Medicine and physician-in-chief of the Johns Hopkins Hospital. He also is an honorary life member of LPA—despite his more than six-foot height.

The multidisciplinary aspects of the Hopkins program reflect the fact that the problems associated with disproportionate short stature can be many and diverse. According to Johns Hopkins' clinic coordinator Barbara Bernhardt, the most common forms of such dwarfism are the following:

Achondroplasia is an autosomal dominant condition producing short limbs and a large head in which leg bowing, lumbar lordosis, and narrowing of the spinal canal may require surgical intervention. It can produce delays in early motor progress, although motor development is eventually normal.

Hypochondroplasia resembles achondroplasia but has milder features and deformities. Diastrophic dwarfism, on the other hand, is an autosomal recessive disorder with a variable range of expression. Clubfeet are present at birth, and lumbar lordosis and kyphoscoliosis develop in childhood.

Cartilage-hair hypoplasia, an autosomal recessive condition, produces fine, sparse, light hair; joint hyperextensibility and lax ligaments; and deficient cellular immunity that predisposes children to infections. A bowleg deformity commonly develops.

Dr McKusick

Ellis-van Creveld syndrome is an autosomal recessive dwarfism recognizable at birth through such features as polydactyly, short limbs, and extra muscle attachments in

continued on page 328

continued from page 323

the mouth. Pulmonary complications may be associated with congenital heart defects and a narrow chest. Knock-knees may need surgical repair.

Spondyloepiphyseal dysplasia (SED) congenita is generally an autosomal dominant disorder producing short-limbed dwarfism. Among other orthopedic problems, osteoarthritis develops in weight-bearing joints in adults. About 50% of those with SED congenita are myopic and retinal detachment is common.

Pseudoachondroplasia is either an autosomal dominant or an autosomal recessive condition producing a short-limbed dwarfism characterized by such features as short fingers, scoliosis, knock-knees, or bowlegs. Degenerative arthritis causes joint pain, particularly in the hips and legs, and may require surgery.

Morquio's syndrome is one of the eight or so mucopolysaccharidoses that have been identified to date. An autosomal recessive condition, it is characterized by a deficiency of the enzyme that breaks down keratin sulfate, and dental x-rays show characteristically thin tooth enamel. Excessive joint laxity, gradual hearing loss, and instability of the cervical spine occur.

At Hopkins, the prevention of such events gets equal billing with genetic evaluation.

"I feel that research, teaching, and the best patient care are inextricably entwined, and I'm not interested in one without all three," says McKusick. Little people have responded positively to this view, and their rapport with the Hopkins staff is extraordinary. "They're friends, not clients or patients," says McKusick, who keeps on display in his office a multitude of wedding photos, baby pictures, and group photos from individual patients, the yearly short stature symposium held at Hopkins, or the LPA conventions.

The Psychosocial Side

At the yearly short stature symposium, topics may include sexual concerns, clothes, careers, and independent living as well as workshops on speech and hearing difficulties and various other medical problems. The two-day symposium, at which participants can receive medical examinations as well as attend lectures and workshops, usually are held at Hopkins. This year, one was held in June at the Jefferson Medical College, Philadelphia.

Open not only to persons of short stature but also to relatives "and other interested persons," the symposia are real events. The usually staid Turner Auditorium and lobby at Johns Hopkins are transformed by crowds of small children playing hide-and-seek while older folk re-establish acquaintances with each other and with Hopkins personnel. For once, participants do not feel a stigma because of their size. (The tendency to assume that little people are handicapped or disabled is often seen in health professionals as well as the general public, according to a 1981 report in the *Johns Hopkins Medical Journal* [148:273-277] by researchers Susan E. Folstein, MD, Joan O. Weiss, Francine Mittelman, and Deborah J. Ross. The investigators noted that in a study of 84 adult dwarfs, "the subjects were normally intelligent, well-educated, and for the most part had normal reproductive capacities. . . . Although all subjects were physically impaired by virtue of their skeletal dysplasias, only those with severe physical abnormalities were handicapped in obtaining education and employment.")

There is some difficulty in finding marital partners, however. Still, Reed E. Pyeritz, MD, PhD, who now heads the medical genetics program at Hopkins, observes that more little people are marrying and having children than in times past, perhaps in part because of the social opportunities provided by LPA. One relatively recent result of this trend is that one in four infants with achondroplasia, the most common form of dwarfism, now is born to parents with the condition. (The majority of cases still arise from spontaneous mutation.)

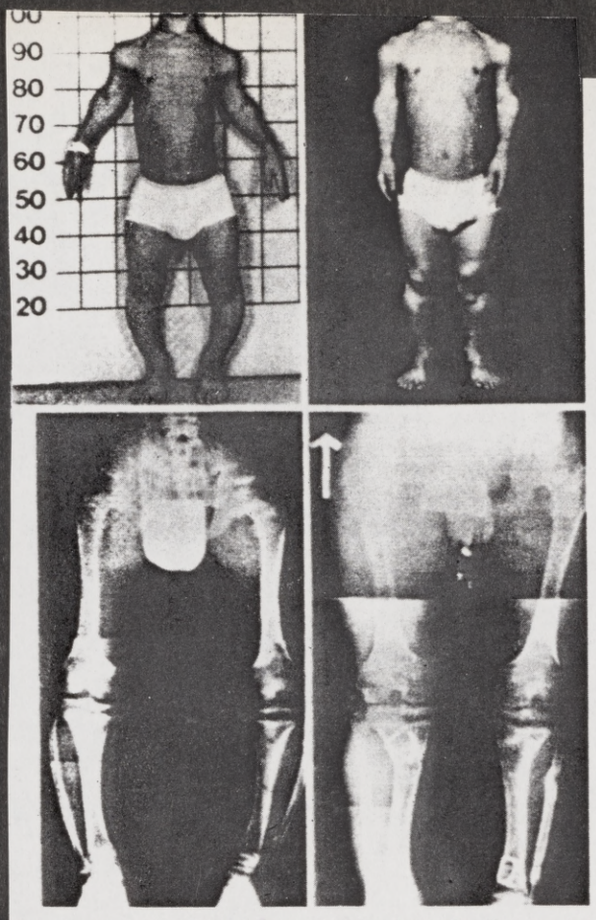
Research currently under way at Hopkins may eventually make possible prenatal diagnosis of at least some forms of dwarfism, Pyeritz says. Such a possibility would be likely to raise serious ethical issues, since most conditions causing short stature do not affect intelligence. However, prenatal diagnosis would be valuable in detecting a fetus homozygous for such a condition as achondroplasia. "Most of those pregnancies go to term, and then the infant dies within a few days," Pyeritz points out.

Shortness is the most obvious feature of dwarfism, but it is not the most serious physical problem. Of more concern are breathing difficulties, for example, or orthopedic problems caused by abnormal bone growth. Consequently, to many little people such specialists as orthopedic surgeons Steven E. Kopits, MD, and Vernon Tolo, MD, and neurosurgeon George Udvarhelyi, MD, are key figures at Johns Hopkins.

Reconstructive Surgery

Kopits, who was chief of pediatric orthopedics at Johns Hopkins until five years ago when he decided to concentrate entirely on those suffering from dwarfism, has a two-year waiting list for reconstructive surgery and has performed about 1,350 procedures. About 34 forms of dwarfism cause multiple orthopedic problems requiring correction, he says. For example, up to 70% of people with diastrophic dwarfism stop walking by ages 7 to 12 years if these problems are left uncorrected. Others may face total disability by their early 20s.

Kopits concentrates his efforts primarily on children, in part to make their lives as productive as possible, and in part to head off what will, if untreated, become multiple and intertwined disabilities. When such work is not done early, "you have fully developed disabilities and to disentangle them is impossible, so you must do crisis care," which is often less than successful, according to Kopits. "Dwarfs are



Correction of bowleg deformity in achondroplasia. ***Upper and lower left:*** *preoperative photograph and radiograph showing bowleg deformity with malalignment and lateral gapping of left knee joint at age 16.* ***Upper right:*** *postoperative photograph at age 18½ with satisfactory alignment.* ***Lower right:*** *postoperative standing anteroposterior radiograph at age 17 showing correction of lateral gapping of left knee. (Reprinted with permission from* The Johns Hopkins Medical Journal, *May 1980.)*

a bona fide subject of medical treatment and care, and these impairments can be prevented," he says.

For example, in the case of pseudoachondroplasia, Kopits observes that "once the patient begins to feel pain in the hips it is usually too late." In this condition, in which the bone ends do not ossify, the legs begin to bow shortly after the child begins bearing weight. The hips are dislocated by the teenage years, and by age 30 joint reconstruction or even replacement may be needed. Realignment of the knees and ankles may also be needed to improve weight-bearing capability and prevent joint flattening, decay, and erosion. To avert such developments, Kopits has developed a reconstructive procedure in children that centers the femoral head in the hip joint, preventing joint destruction and, for reasons as yet unknown, also causing the femoral head to ossify.

In fact, Kopits, working "syndrome by syndrome" with radiologists, other surgeons, and anesthesiologists at Hopkins and at the Children's Hospital and Center for Reconstructive Surgery in Baltimore, has devised a host of innovative "custom" surgical approaches and is now trying to record and document his work of 15 years in a textbook.

To illustrate the constellation of problems characteristic of the various skeletal dysplasias, he recently discussed his experience with 50 patients with SED congenita: 63% showed instability of the cervical spine, 43% myelopathy, 96% a progressive developmental deformity of the hip leading to subluxation or dislocation, 41% severe scoliosis, 80% metatarsus adductus, and 43% knock-knees or bowlegs. By contrast, in nearly 500 cases of achondroplasia, only four cases of hip involvement were seen.

Another example is diastrophic dwarfism, in which compression of the cervical spine, kyphosis and severe scoliosis, hip and knee dislocations, and clubfoot and upper limb deformities may occur. Until recently, many physicians thought even the clubfoot was uncorrectable, but Kopits has had good results when combining correction of that defect with corrections of the other associated problems.

In some forms of dwarfism, however, Kopits is reluctant to intervene drastically. For example, with the exception of Morquio's syndrome and Maroteaux-Lamy syndrome, the mucopolysaccharidoses generally cause mental abnormalities as well as physical problems. "I would never be as active in terms of treatment with someone whose brain is not normal," he observes, pointing out that most of his patients must undergo 90 to 100 hours of surgery to achieve adequate correction.

'The Model Is Exportable'

Physicians from all over the world have carried the principles of the Hopkins program home with them. "The model is exportable," says McKusick, adding that the LPA is also active in such countries as Australia, France, the Netherlands, England, Germany, and Denmark. Physicians trained by McKusick have established regional centers in such areas as Torrance, Calif; Vancouver, British Columbia; Kansas City; Wilmington, Del; and Philadelphia. In one collaborative project, growth statistics for such conditions as diastrophic dwarfism and SED congenita were pooled by five centers to develop growth tables.

Medical geneticist Laird Jackson, MD, of Jefferson Medical College, says his rationale for developing a Philadelphia program was "to make my interest in short stature and skeletal dysplasias more public." Thus he works with colleague Charles Scott, MD, the Wilmington center, and the local LPA chapter to

continued on next page

Dr Kopits and patient

continued from previous page

provide diagnosis and care. "We're not trying to duplicate or compete with Johns Hopkins but to provide more convenient services for little people, so they don't have to travel to Baltimore for everything," Jackson says.

Although some orthopedic work is performed at hospitals associated with these centers, Kopits says, few surgeons have so far expressed interest in learning the techniques he has developed. He has trained just one, João Thomazelli, MD, who plans to open a treatment center in São Paulo, Brazil, at the Federal School of Medicine. In an effort to engender more interest, Kopits has established a Little Peoples Research Fund in Baltimore and hopes to establish an orthopedic teaching program. After first becoming "hooked" on this area of research and treatment by McKusick about 15 years ago through an invitation to the summer symposium, Kopits reached a point where "five years ago, the big decision of my life was to commit myself completely to little people, and I want others to build on it."

In the meantime, little people continue to come to Baltimore, Kopits and other Hopkins personnel attend LPA meetings around the country, and about once a month Kopits and assistant Dianne Davis hold what they call "country clinics," spending two or three days at various hospitals around the country—Miami, Cleveland, Denver, Milwaukee, Dallas, and Peoria, Ill, for example—to follow up on patients and see new ones.

Thus, little people, who already have found good friends in Baltimore, are now finding them elsewhere as well.—by SUSAN LAWRENCE

One (little) couple's ordeal

Like most products of the post-World War II baby boom, Ernie and Dolores Ott are busy with the complexities of young adult life. Ernie, who earned an MBA five years ago, is firmly ensconced in computer sales with a large corporation. Dolores, a brand-new, first-time mother, recently left her job as a local government buyer for family life. With a newborn son, the Otts are preparing to plunge from apartment living into home ownership.

The Otts are not, however, entirely typical. When Dolores underwent her recent cesarean section, Ernie was in the next room—covered in plaster from chest to toes and on a brief leave of absence from the orthopedic hospital where he is about halfway through a six- or seven-month stay for osteotomies and reconstruction of the hips, knees, and ankles.

Both Otts have spent much time in hospitals. Dolores has undergone ordeals similar to Ernie's, including bilateral hip replacements and knee reconstructions. Her surgical experiences were marked by delayed healing and many setbacks, and now, as she visits her husband, bringing the baby with her every other day, she pays close attention to his care—and coaches him carefully.

"You just have to take it day by day," she told *JAMA* MEDICAL NEWS over lunch in the hospital cafeteria a few weeks ago. Ernie has a similar view, although he adds that no amount of discussion or anticipation really prepared him for life in a spica cast, punctuated by yet another day on the operating table every other week or so. So far, his only complications have been relatively minor ones—but they have slowed down the surgical timetable.

The hospitalizations have been necessary because both the Otts have pseudoachondroplasia, a form of heritable skeletal dysplasia, and stand about 4 ft tall. As well as short stature, pseudoachondroplasia causes severe orthopedic problems of the lower limbs that can sentence young adults to life in a wheelchair if the defects are not corrected surgically.

When it became clear to Ernie that his mobility was becoming seriously impaired, the Otts began making plans for a major disruption of their lives. Although they had to give up their condominium and rent an apartment in Baltimore for the hospitalization period, they are able to maintain ties with family and friends in the surrounding area. Many little people must come to Baltimore from much farther away, giving up social supports that are especially needed during such a long ordeal. Ernie could also arrange for a year's leave of absence from his job and is adequately insured. Not all who need the extensive reconstructive services offered at the Johns Hopkins University School of Medicine or the Children's Hospital and Center for Reconstructive Surgery, Baltimore, have been as fortunate.

It is too early to tell whether the Otts' child has inherited pseudoachondroplasia, which geneticists think has several forms that may be transmitted dominantly or recessively. If he has, at least he will not have to interrupt his adult life for surgery, because orthopedic surgeon Steven E. Kopits, MD, has devised a number of procedures for young children who are dwarfs that reduce the joint damage and destruction they would otherwise experience in later life.

Although it is not an easy time for the Otts, they continue to work actively with the Little People of America organization, where they first met. Last year, Ernie helped organize an international meeting of little people held in Washington, DC. He also is a member of the board of the newly formed Little People's Research Fund, which funds research into the disabling aspects of dwarfism and their prevention, patient care, and education and training of orthopedic specialists.

Kopits hopes the day will come when little people have to cope only with being short. And Ernie adds, "We don't see ourselves as freaks—just as normal people with some physical limitations."—S. L.

Ewoks Debbie Carrington (left) and Margarita Fernandez vamp in a California redwood forest.

Although the degree of Ewok cuteness was fine-tuned by makeup artist Stuart Freeborn and his staff, who built them from designs by visual effects director Joe Johnston, some technical problems could not be corrected. To Lucas' disappointment, the eyes and mouths of the Ewoks couldn't move independently, and, as a result, the creatures have a slightly wooden look.

Such flaws are invisible in the Ewoks' most thrilling scene: a rocket-scooter chase through a redwood forest. The effect was achieved with surprising simplicity. It was shot by a cameraman walking through the trees with the film turning at a very slow rate of speed. When the film was shown at normal speed, the motion was greatly accelerated—especially when intercut with shots of the scooters in flight.

For some Ewoks, who were paid a minimum of $298 a day for their troubles, such movie magic was hard to come by. "The costumes were like saunas," says Debbie Carrington, 23. "The wardrobe people were constantly bringing us Gatorade." For 3′10″ Debbie, life as an Ewok had a happy ending. On the set she met 5′9″ extra Bob Eslick, 21, who played a storm trooper. Last December, after graduating from the University of California at Davis, she moved to Los Angeles with Eslick. "He calls me his Ewok love," she says. Debbie is currently appearing as Alvin the Chipmunk in a traveling show for kids.

"I'm now dancing to disco instead of creeping around on the forest floor," she observes.

The most compelling complaint about the Ewoks in *Jedi* is that the audience doesn't see enough of them. Margarita Fernandez, who has appeared as Birdie the Early Bird in McDonald's television commercials, can attest to their popularity. Six months ago, the license plate on her Toyota—EWOK 1—was merely a curious combination of letters. Now, she says, "when I'm driving down the freeway, it almost causes an accident." □

THE FORCES BEHIND *JEDI*: MAKING MOVIE HISTORY TOOK LUCAS & CO. TO THE OUTER LIMITS

Screen

The noise generated by 150 actors and crew members resounded in the cavernous sound stage at Elstree studios outside London. Equipped with cool-air dryers, assistants hovered around Jabba the Hutt and his pig guards, trying to refresh the actors inside the hot, cumbersome costumes. Smoke that was frequently sprayed around to give Jabba's palace "atmosphere" irritated noses and eyes. In the midst of the pandemonium stood director Richard Marquand, nervously sucking in his cheeks. It was just another long, exhausting day in the $32.5 million-making of Return of the Jedi, *this summer's monster hit. To throw off the inquisitive during filming, the movie was code-named* Blue Harvest. *When T-shirts were made up for cast and crew, executive producer and* Jedi *mythmaker George Lucas could not resist adding a tagline: "Horror Beyond Imagination." Asked what he meant, Lucas replied, "That's the making of the movie, not what the movie's about." In the following pages the behind-the-scenes and behind-the-masks people of* Jedi *discuss the frustrations and exhilarations of creating the No. 5 box-office success of all time.*

Amidst all the plot convolutions of who Princess Leia *really* is and who Luke's father *really* was, *Return of the Jedi* is stolen by the Ewoks, 40 little creatures in furry suits. Scaled-down versions of giant Wookiees, the plucky Ewoks reside on a jungle planet in harmony with their environment. The objects of moviegoers' affections, the Ewoks were the inspiration for jokes on the set of *Jedi*. How does an Ewok get across the road? It woks. What does an Ewok have in its ears? Ewax.

The uncomfortable Ewok costumes were made of foam rubber covered with specially treated cotton and Dacron.

The 66 dwarfs and midgets who played the Ewoks generally kept to themselves during filming. Dwarfs were preferred for the roles because their limbs are not proportional and therefore look less like actors in costumes. There were in fact two separate groups of Ewoks: The English cast shot interiors at Elstree and an American cast did the outdoor sequences in Crescent City, Calif. Ranging from 2′11″ to 4′8″ in height, many of the little people had worked in the 1981 comedy *Under the Rainbow,* which starred Chevy Chase and Carrie Fisher, and they were known to *Jedi*'s casting directors. When *Jedi* filming began, Fisher exclaimed, "Oh, no, not midgets again."

Always fascinated by anthropology, George Lucas had an active subplot about a Wookiee planet and culture in *Star Wars,* but prior to filming, he cut it out for the sake of pacing. He recycled that notion into *Jedi*'s Ewok society. Lucas wanted to illustrate a lifelong belief that faith in a cause can help people overcome technologically superior opponents. He also wanted the Ewoks to be more approachable than the other aliens in his bestiary. "Keèp them a little cuddly, so we want to hug them a little," he advised *Jedi* director Marquand. But when Lucas first saw the Ewok costumes, he thought they had a case of the "terminal cutes." The performers weren't thrilled, either. Recalls 3′4″ Margarita Fernandez, 24, "When we first looked at each other as Ewoks, we thought 'Yuk.' Then they began to grow on us."

An adorable Ewok is also a marketable Ewok. Toys and other spin-offs from *Star Wars* films are a merchandising bonanza, and Lucasfilm has approved some 40 licenses for *Jedi*-related goods. The movie Ewoks were designed with an eye to having the appropriately furry 'n' fuzzy appeal to little consumers. Kenner Products plans to deliver the first shipment of stuffed Ewoks to toy stores late next month in plenty of time for the Christmas shopping season.

TERRY SMITH

"I'd love to play a part where I'm not hidden by costumes, a part where I can wear ordinary clothes," says 7′2″ Peter Mayhew, who is now out of work.

Playing Chewbacca the Wookiee is a tall order

A 7′2″ actor can't play just anyone. So Peter Mayhew was thrilled when the role of Chewbacca, Han Solo's simian sidekick, rolled his way. The oversize Englishman had only one previous acting credit, as a monster in 1977's *Sinbad and the Eye of the Tiger,* when a buddy recommended him to the Lucas team casting *Star Wars.* It was the start of a long and lucrative relationship. And an affectionate one—Mayhew is very fond of his Wookiee alter ego. "He's basically good and kind and looks after his group," says Mayhew, 39. "The only thing he can't do is talk."

Acting inside a latex mask and furry costume isn't the same as essaying Hamlet. But Mayhew attempts to convey Chewie's feelings through mime techniques. "The way I stand and the tilt of my head can convey tension, happiness, fear or anger," he explains. I've never had an acting lesson in my life. It's largely instinct. As soon as that Chewbacca mask goes on, my personality changes."

Mayhew's entrée into show business was as unconventional as his size. Eight years ago he entered a *Guinness Book of World Records* contest for the biggest feet in Britain. Although a size 16 EEEE, Peter surprisingly didn't make the cut. However, a newspaper photograph of Mayhew caught the eye of the *Sinbad* casting director, who was looking for larger-than-life-size fellows to play ogres. Offered three months of location work in Spain and Malta, Mayhew leaped at the opportunity. Afterward, he says, "I thought, 'Great, this is what I was built for. This is what I want to do.' "

Ever since he started out as a 10-pound baby ("My weight was in the length, not in the girth"), Mayhew has found life "a bit of a problem." The only oversize member of his family, Peter grew up in Surrey, where his father was a policeman and his mother a housewife. Peter was 6′ by the time he was 12 and his full height at 17. "I was growing at the rate of some two to three inches a year," he recalls. "I used to think, 'Oh God, how am I going to manage?' " Dropping out of school at 15, Peter held a variety of manual jobs. "Once I was a warehouseman, and it was one of the few jobs where my height was an advantage," he says. "When the high shelves needed stacking, they'd shout, 'We don't need a forklift. Just get Pete!' " His most rewarding pre-showbiz job was a 10-year stint as a hospital porter. "Not a lot of money," he says, "but if you do a job that you enjoy, that's half the battle."

Mayhew returned to his $90-a-week porter's post after finishing *Sinbad,* and then again after *Star Wars,* when his work as Chewbacca did not win him other roles. Because Lucas initially wanted to keep the people behind the characters a secret, "there was very little publicity for us," Peter says. When it came time for him to do *The Empire Strikes Back,* however, Mayhew threw in his porter's towel for good. A tiny share of the enormous profits of *Empire* and *Jedi* has provided Mayhew with financial security. He owns a four-bedroom, chalet-style house just south of London, where he lives with girlfriend Gwen Davis, 35, a charity fund raiser. Although Chewbacca is beloved by children, Mayhew has none of his own. "That's an expense I can do without," he says of a family. "I love doing promotion work with children, but I do like to feel that once I shut my front door, nobody is going to come knocking."

Mayhew, who weighs 242 pounds, shed 15 pounds during the four months of filming each movie. He shot the desert scenes of *Jedi* in the 120° heat of Yuma while wearing a 25-pound woolly suit. "Between takes I'd turn into the wind with my arms in the air, like some shaggy windmill, to cool off." Since Chewie often gets physical, there were three identical costumes for Mayhew. "After a morning's shooting they could get a bit sweaty and smelly," he says. "They were then dry-cleaned, powdered and put back into service looking sleek and smooth."

Despite the difficulties, Mayhew has enjoyed making the trilogy. "It's like a family," he says. "It's a great atmosphere." One of his fondest memories is the shooting of the scenes with the Ewoks amid northern California's redwoods. "I'd get into the forest, look up, and the trees just went up and up and up," says Mayhew. "For once I felt very, very small." □

Previous page: the principals of *The Ewok Adventure:* left-to-right, friendly Ewok, Mace (Eric Walker), Jeremitt (Guy Boyd), Catarine (Fionnulla Flanagan), Cindel (Aubree Miller), Wicket (Warrick Davis).

Those cuddly, furry little space creatures who helped Luke Skywalker and his companions defeat the dreaded Empire are returning to celebrate the holidays. And best of all, this time you won't have to pay five bucks to see them cavort across the screen.

The Ewoks are trooping into your living room for two hours of holiday cheer this month, courtesy of George Lucas and ABC television. The special, entitled *The Ewok Adventure*, is a multi-million dollar visual-effects extravaganza, featuring the furry race in an *all-new* adventure that has almost no reference to the characters or events in *Return of the Jedi*, the movie which introduced them.

Tom Smith, formerly the General Manager of Lucasfilm's Industrial Light and Magic visual-effects house, is the special's producer, while Lucas serves as executive producer. And Smith promises that *The Ewok Adventure* will be unlike any story you've *ever* seen on television.

"Nothing, with the possible exception of *Battlestar Galactica*, has had as many special effects as we are putting into this film," Smith says, quickly adding that "this is *not* a spacey movie with a bunch of ships flying in and out of starfields. Ninety-nine percent of the action occurs on Endor, the Ewoks' planet."

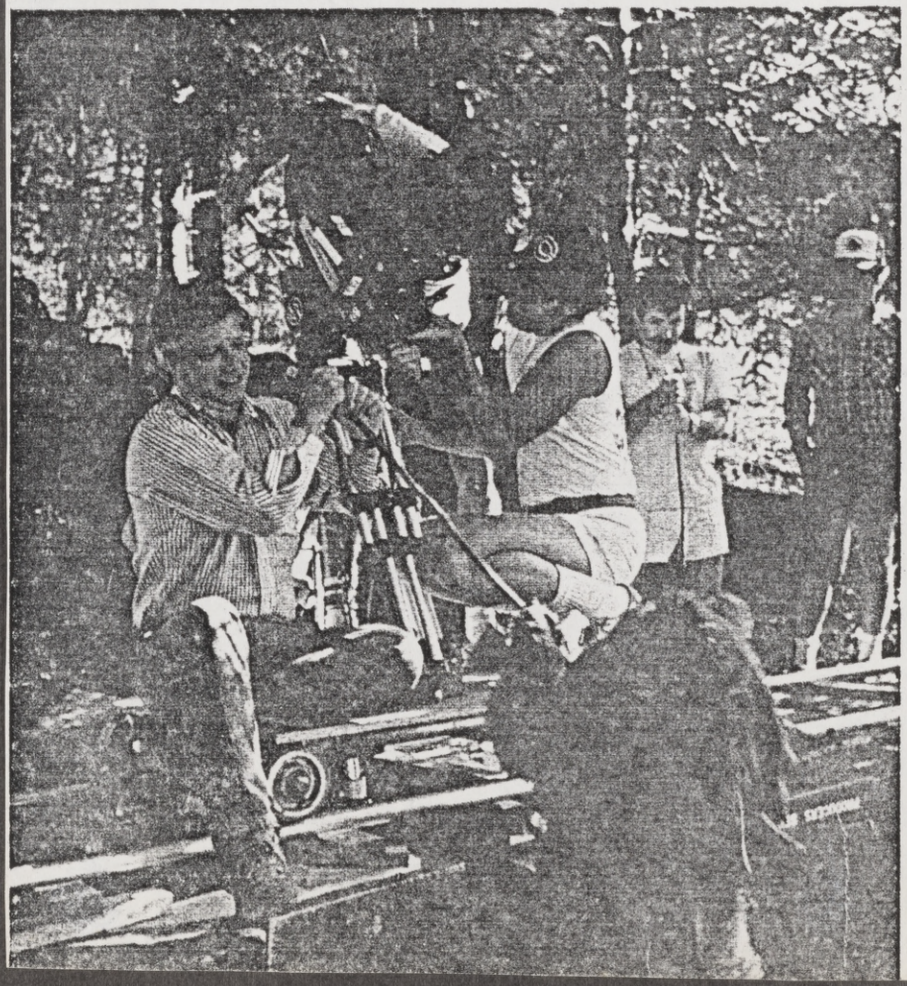
As with most Lucasfilm projects, its storyline is shrouded in secrecy. Smith does reveal that a spaceship piloted by a human family crash lands on Endor. The parents are separated from their two children and captured by a hideous monster, the Gorax. Left on their own, the children, a four-year-old girl and a 15-year-old boy, must now try to survive in and around the damaged spacecraft. Fortunately, they are befriended by Ewoks, who lead the kids on a trek to rescue the adults from the Gorax.

The cast is filled with mostly unfamiliar faces. Guy Boyd portrays Jeremitt, the father, while noted stage actress Fionnulla (*How the West was Won*) Flanagan is Catarine, the mother. And 15-year-old Warrick Davis reprises his role as Wicket, the friendly Ewok who first encountered Princess Leia in *Return of the Jedi*.

Aubree Miller, who plays the human daughter, Cindel, has *never* acted before. Miller—only four years old—was discovered in one of the open auditions Lucasfilm conducted in San Francisco and Los Angeles. Fifteen-year-old Eric Walker, who has had several bit parts in movies, is her brother, Mace.

"Most of the Ewoks are played by Little People. The tallest is less than four feet high," Smith says. "There's much more acting involved for the Ewoks this time.

On location, director John Korty rehearses an Ewok.



ALL EWOK PHOTOS: COPYRIGHT 1984 LUCASFILM LTD.

Producer Tom Smith and his adventurous star Wicket (Warrick Davis).

complex with a gigantic creature and the only way to achieve that is with blue screen effects and through matte paintings. We're also using some stop-motion. Phil Tippett, who won an Oscar, and John Berg are doing some marvelously articulated creatures for this film."

Smith stresses that ILM is concentrating on developing effects which will "work well on the small screen. With *Star Wars* on TV, in some respects, we had problems. What looks bad on TV is when you have multi-element shots and have slight color differences between those elements," he explains. "These differences are accentuated on TV. That won't happen on *The Ewok Adventure*.

"But we are giving this project the feature film treatment because we don't know any better right now."

The theatrical treatment includes a full, 80-piece orchestra performing the soundtrack. John Williams will *not* be scoring *The Ewok Adventure*. Those responsibilities have been awarded to Peter Bernstein, son of conductor and soundtrack veteran Elmer (*The Magnificent Seven*) Bernstein. This is Peter Bernstein's first major movie after scoring a string of low-budget flicks, including Bo Derek's *BO-lero*.

For his part, Smith is enjoying his return to active film production after four years spent heading Lucasfilm's ILM facility. There, he supervised the special FX teams sculpting the *Star Wars* saga as well as *Dragonslayer, Poltergeist, Star Trek II* and *III, Raiders of the Lost Ark, Indiana Jones* and *E.T.*

"Four years of doing visual effects is enough for me," he says. "The experience was very good, but it began to get repetitious."

Smith produced 30 to 40 16mm movies for Encyclopedia Brittanica before joining Lucas. He was eager to return to similar duties. "Being at ILM," he laughs, "it was like producing films which were *always* stuck in post-production. I do enjoy it, but now I get more of a sense of authorship, of steering the course of a film. Before, I was always serving the needs of the production."

Smith has no screen projects in the offing as of yet. Instead he's using his free time to craft a book for Doubleday recounting his ex-

Ewoks

(continued from page 63)

periences at ILM. "It will have lots of photos and discuss the special effects achieved, step by step, film by film during my four years at ILM," he explains.

Thanks to the *Star Wars* track record, *The Ewok Adventure* is expected to garner huge ratings, despite the heavily competitive November ratings sweeps environment. Beyond its network commercial success, Smith sees *The Ewok Adventure* as the kind of entertainment product that Lucasfilm will concentrate on creating in coming years.

"It's very difficult doing a *Star Wars* or a *Jedi* that involves three years of work," Smith says. "I suspect we will be doing more things like this movie for television. They will be projects that can still use the story ideas of George Lucas and the talents of ILM, but these movies will be less ambitious. They *won't* be three-year projects."

The Ewok Adventure, he says, was a nine-month effort. "It was a lot more manageable than a *Star Wars* film. In two or three years, George can get his ranch [the Skywalker Ranch filmmaking complex] done and get a bearing on what kind of activities he wants to be involved in."

ABC, of course, would like to see more exploits on Endor with the Ewoks—perhaps as one special a year or as a regular series.

"That's the *first* thing the network asked us," Tom Smith concedes. "They said: 'Can this be a pilot for a TV series if it works out?' We're not approaching the project that way. This is a one-of-a-kind story and I know *I'm* not interested in doing a series. I don't think George is interested in churning out a TV series, either."

But, and there are always buts, "if it works, and the audience likes *The Ewok Adventure*, maybe we *will* do more." ★

PHOTO: TERRY CHOSTNER

Wicket (Warrick Davis) tries to comfort a suffering, if human, Cindel (Aubree Miller).

Rescued by Ewoks, Catarine (Fionnulla Flanagan) and Jeremitt (Guy Boyd) await the escape of their son, Mace, from the Gorax.

EWOKS IN YOUR LIVING ROOM!
George Lucas' New TV Adventure

HEY THERE, EWOKS

. . . The scenes in *Return of the Jedi* featuring the Ewoks are a direct steal from "The Tiddley-Wink Warriors" by Poul Anderson and Gordon R. Dickson, copyright 1955 Fantasy House, Inc. This story featured a race of "Teddy Bear" aliens called Hokas. George Lucas hasn't had an original idea in his life. However, if we do accept his explanation that his movies are tributes to the writers whose ideas he steals, why doesn't he give *them* credit where it's due?

David Richards
63 Fosters Road
Greenacres
S.A. 5086
Australia

When an established theme, concept or idea is incorporated by a filmmaker into a new project, it is called "homage," not theft.

"The Ewok Adventure"
A made-for-TV movie
See Story Page 3

Cover Story By Seth Cagin

Lucas's first made-for-TV movie
"The Ewok Adventure"

Now that George Lucas is bringing his creatures to television, comparison to that other master of the fantastic, Walt Disney, is inevitable. Quite simply, George Lucas is Walt Disney's unqualified successor.

The man behind "American Graffiti," the "Star Wars" films and Indiana Jones is, like his predecessor in mass-appeal fantasy, a multimillionaire many times over. He is the overseer of a company that bears his name, Lucasfilm. Like the house that Disney built, it is a vast empire of special-effects shops, film studios and other related businesses, located at a notable distance from Hollywood in Northern California's idyllic Marin County. And, like Disney at the peak of his powers, Lucas supervises hundreds of employees in the execution and marketing of his solid-gold images.

Lucasfilm cheerfully shrugs off the insistent comparisons with Disney, and yet "The Ewok Adventure," a made-for-TV movie airing Nov. 25 on ABC, bears all the earmarks of Uncle Walt's elaborate production, meticulous attention to detail and direct emotional appeal to children.

The film features those fuzzy, pint-sized extraterrestrials, the Ewoks, who made their debut in "Return of the Jedi," the third chapter of the "Star Wars" trilogy. In their new adventure, the kindly Ewoks come to the aid of two children separated from their parents when the family star cruiser crash-lands on the Ewok's home planet.

"The Ewok Adventure" represents yet another step forward in Lucas's innovative career.

This TV movie includes more than 170 special effects, more, in fact, than were included in "E.T." Not only were the elaborate special effects costly, but there were unusual production problems associated with the making of the film, too. The Ewok costumes and makeup were unwieldy; there were many real animals utilized who were not always ready to perform on cue; and the film's human stars, 14-year-old Eric Walker and 4-year-old Aubree Miller, were subject to California's strict child-labor laws. Thus, Aubree could work only three hours each day.

Although the barriers were overcome, the movie required a huge production budget. "It was far more than what is normally spent on a television movie," says producer Thomas Smith, formerly head of Industrial Light and Magic, Lucas's state-of-the-art special-effects company. But Lucasfilm hopes to recover its costs, which cannot be made up from U.S. television alone, by releasing "The Ewok Adventure" to theaters overseas.

Does "The Ewok Adventure" point to more television work from George Lucas? "I imagine George will wait to see the results," Smith says. "At ILM we're used to giving 100 percent. The idea here was that we could give 98 percent at half the price. It's that last 2 percent that kills you. And we got results that are first class. If people understand what we were trying to do and like what we've achieved, then I suspect George will be interested in doing more."

Individual characteristics have been developed for each Ewok."

And, like the Klingons in *Star Trek III: The Search for Spock*, these alien creatures mouth their own unique language.

"The film is in English, but the Ewoks *will* speak Ewokese," the producer explains. "If someone pays careful attention, as with *Shogun*, one can begin to learn the language. We have a staff of linguists who developed it. Randy Thom, our sound designer, is doing an incredible job on this aspect."

The Ewok Adventure utilized many of the same costumes and sets created for *Jedi*. It was shot entirely in Northern California by director John (*Autobiography of Miss Jane Pittman*) Korty. "We have *every* piece of real estate within a block of here filled with Ewok sets," Smith laughs. The screenplay is by newcomer Bob Carrau from a story by George Lucas.

"George liked the Ewoks and decided he would like to do a small TV special on them," Smith recalls. "He had this story in mind and he wrote it with Bob Carrau. Bob is in his early 20s. He has *never* done anything like this before. Bob worked for George as an aide and now, George is giving him a break."

As the writing progressed, so did the scope of the once "small TV special."

"George had in mind a kind of one-hour family story. Now, it has turned into a wide-screen adventure involving Ewoks, teenagers, parents and several monsters," Smith says. "It will be released as a theatrical feature overseas."

Although *The Ewok Adventure* is billed as a "Christmas special," don't expect reindeer, Santa's castle or Burl Ives warbling about the holidays. The program is slated—at press-time—for airing this month, probably on Sunday, November 25. (Check your local listings).

"It's Christmasy *only* in the sense that the family is rejoined at the story's end and there's a very warm feeling," Smith says. "This *isn't* a Santa Claus, snow-on-pine-trees type of movie."

Filmed as *The Ewok Movie* with *The Ewoks of Endor* and *Caravan of Courage: An Ewok Adventure* as alternate titles, the project has been occupying Lucasfilm's attention since March. In mid-August, the filmmakers were still working on special effects and some live-action scenes while editing continued, to meet an October delivery date. Among the work still unshot in late August was a "totally animated, magical pixie character" and a live-action Ewok hang gliding sequence (partially previewed in a photo in STARLOG #88).

"There are a tremendous amount of ambitious effects," says Smith. "It is, by far, the biggest project that ILM has going right now. There are at least 25 matte shots and 50 blue screen and other FX shots. And as we edit, we keep finding places where we can insert more effects. It's so easy to do, since we have the biggest FX house around right here. We're trying to resist that temptation.

"We are dealing mainly with problems of scale. Much of the film takes place in this

Addie's World

By Adalene Ross

Is there a disabled person on your Christmas gift list?

If so, I have for you today a marvelous idea for a present that you might otherwise not know about.

It is a magazine published exclusively for the disabled, who would like to see the world every bit as much as those of us without physical disadvantages, yet are thwarted in so many ways.

The publication is Itinerary Magazine. It's hot off the press every two months, and for a mere $7 dollars-per-year subscription you could be doing an enormous favor for someone.

Itinerary is published by Robert Zywicki, a recognized authority in the world of disabled travel. Zywicki has suffered with rheumatoid arthritis for 21 of his 39 years, but you can't say it's slowed him down much.

A former newspaper editor with the lure of travel in his blood, Zywicki often found himself discouraged at the difficulty he had maneuvering in a wheelchair onto planes or trains, or aboard ship.

And, nearly disheartened at the lack of conveniences — total nearly always — for the disabled in hotels and restaurants, not to mention museums and all the sightseeing places the everyday tourist takes for granted.

With the courage that most of us who go barreling through life without pause to consider our good fortune and having two legs and arms that work, can never know, Zywicki decided to take action on behalf of himself, eventually for other disabled. Itinerary is one result of his efforts.

"With the growing number of persons with disabilities who are discovering — or rediscovering — the joys of traveling, comes a need for a source of information that will help them with their special needs," says the Itinerary publisher.

"While there are numerous publications about travel for able bodied persons, Itinerary is the world's only magazine geared to the special needs of travelers with disablities," he adds.

Zywicki's goal — and that of his wife Betty who since 1981 has been working with her husband to produce this excellent printed source material — is to provide "much-needed and often hard-to-find information about accessible travel destinations, transportation, tour operators who specialize in services for the disabled, access guides and travel books, travel resources for the disabled and other data that make the difference between an enjoyable and safe trip and one that could be disastrous."

The Zywickis travel the world to research material for Itinerary. They often conduct international tours — popular you bet for the wheelchair-bound may join up. Most of all the material in the magazine is written by people with disabilities — who know firsthand the difficulties of trying to get around in a world planned for everyone but themselves.

All holiday subscriptions to Itinerary begin with the January 1985 issue which features a report on the nation's top hotel and motel chains — a guide for the disabled. Handsome gift cards bearing the giver's name will be sent to recipients.

Subscriptions are available only by mail from Box 1084, Bayonne, NJ 17002. Subscriptions must be pre-paid.

Robert Zywicki recognizes that he can't change the world overnight for the disabled traveler. But he sure can go a long way to smooth it out some.

By the way, you'll notice that Zywicki never refers to the "handicapped" traveler. The word is "disabled." They are not necessarily the same thing.

Synthesizing Human Growth Hormone Is A Step Closer

BERKELEY (UPI) — Scientists are a step closer to synthesizing the human growth hormone—that tiny, complex chemical chain of 188 amino acids which control such factors as body size and breast development.

Dr. C. H. Li, director of the Hormone Research Laboratory at the UC Medical Center in San Francisco, Tuesday told a science writers seminar that man-made development of such a hormone could control breast cancer and cure dwarfism in children in addition to producing bigger people and bustier women.

Dr. Lee said he and other researchers have mapped the chemical structure of the milk-producing hormone of sheep. By comparing it to human growth hormone, which Li mapped three years ago, he hopes to isolate the sections which control growth and those regulating human milk production and breast development.

The Human Growth Hormone (HGH) is a chain of 188 amino acids made in the pituitary gland of the brain. It was identified 41 years ago and has been extracted from the donated pituitary glands of dead people. But each case requires the hormone taken from hundreds of glands. A synthetic hormone would solve the supply problem.

HGH also controls milk production—a function handled by a separate hormone in animals. Li described recent tests in Mexico where nursing mothers were given the hormone daily for a week. Their infants gained three times as much weight as an average child during the period.

But he said the primary purpose of his research is development of a modified hormone to inhibit the growth of breast cancers.

Li, who has been studying HGH for 29 years, wants to isolate the portions of the amino acid chain controlling growth and milk production, map their structures, and then synthesize them. He hopes to unlock the mystery by mapping the ovine lactation of sheep hormone, a chain of 198 amino acids.

The science conclave also heard UC psychologist Joe Kamiya predict future "brain music," created by controlling the brain's electronic waves.

"We could convert your brain's alpha waves into sound patterns," he said. "You would find the rhythm that makes you feel the best, and change the tone patterns as you feel like it."

Kamiya said subjects can be tought to control their alpha brain waves and suggested that this is similar towhat Zen and Yoga masters do as they medita'e.

He said other experimenters believe that the brain's Beta and Theta waves are connected with tension, mental effort and decision-making.

Kamiya said learning control of the alpha wave could help fight blood pressure, heart rates, nervous sweat, and tension headaches.

He predicted future school courses in "self awareness," in which a youngster would be taught what happens to his system when he becomes angry, dreamy, sexually stimulated, hungry or thirsty.

Hip replacements: success rates high

I'm scheduled for a hip replacement operation next month, something I approach with growing apprehension. My doctor tells me not to worry because he performs this operation all the time. I'd feel better if I knew something about the success rate and what to expect.

The good news about the nearly 75,000 hip replacement operations performed in this country each year is that nine out of 10 are successful. Relief of pain and return to useful function can be expected in the vast majority of patients, according to the consensus at a National Institutes of Health conference held last year.

The surgery is major—involving the replacement of the upper part of the thigh bone and hip socket, held in place with plastic cement—and should be done by an orthopedic surgeon with special interest and expertise in this area, says the conference report. It should also take place in a hospital where the operation is performed frequently.

In most cases, hospitalization is required for two to three weeks, followed by several more weeks using walking aids. Most patients regain relative independence in about three months.

The patient's activities after recovery should include all those involved in daily living—unlimited walking, driving a car, dancing, sex, etc., according to the NIH. To be avoided are repetitive activities that overload the hip, such as jogging,

continued

jumping, and racquet sports. General physical fitness is especially encouraged.

Synthetic hip relieves much of agony of arthritis

The constant pain in Edith Cronin's right hip had severely limited her activities for several years and cast a shadow of gloom over her future.

"I was in agony," the 65-year-old San Carlos resident says, describing the unending torment caused by severe degenerative arthritis.

Mrs. Cronin had been taking physician-prescribed pain medications with poor results. Walking was excruciating. Getting out of a chair was an ordeal.

"I couldn't even lay comfortably in bed at night," she declares.

However, a two-hour operation on April 20 gave Mrs. Cronin a chance to experience what it's like to be pain-free for the first time in years. In surgery, her deteriorating hip joint was replaced by a stainless steel and plastic prosthesis that, in her case, is better than the real thing.

"When we cut out the arthritic part of the bone, we cut out the arthritic pain," explains Dr. Edward Katz, who performed the operation along with Dr. Frank Ruys at Sequoia Hospital in Redwood City.

"I wouldn't advise her to jump off a 6-foot fence," adds Ruys. "But, she should be almost painless at a normal daily activity level."

A month after her surgery, Mrs. Cronin — still on crutches — has no qualms about the possibility of another operation in her left hip if arthritis in that joint becomes severe enough in the next few years.

In fact, Ruys says, just about every joint in the body — except those in the spine — can now be replaced with synthetic implants. Surgeons are fitting victims not only of degenerative and rheumatoid arthritis but also birth defects and bone-destroying traumatic accidents with new knees, shoulders, ankles, elbows and wrists. The smallest currently replaceable joints are those located at the base of the fingers and toes.

"If you could live long enough, we could eventually replace every joint in your body," Katz declares. Better materials and improved surgicial conditions are being developed all the time so that the success rate in hip replacement — the most common of joint implant procedures — now averages about 95 percent.

In fact, Ruys says, hip replacement has even helped some people with absolutely frozen or ankylosed hip joints to walk again with the help of a walker or cane.

Most joint replacement patients are more than 60 years of age while the oldest ever at Sequoia was a 92-year-old woman who received a new hip. Because increasing age can present added risks in surgery, patients are carefully screened and surgery is postponed until basic measurements of health such as blood pressure can be brought into a safe range, Ruys stresses.

"Sometimes, the patient's heart is so bad that we can never take on the risk of joint surgery," Ruys explains.

Hip joint replacement surgery begins with an incision made on the side, right over the hip itself. The length varies depending upon the amount of fatty tissue and how deep the surgeon needs to go to gain adequate working space for installation of the new joint.

The surgeon dislocates the hip and prepares the bony socket to receive the plastic cup and cement by enlarging and shaping it with special tools. The plastic socket is then cemented into place.

The shaft of the femur, the long bone of the thigh from which the damaged ball was removed, is prepared for a stainless stel stem, sized to fit the patient. The stem is cemented into place and the two implant parts are brought together to reunite the hip.

While still in the operating room, the surgeon tests the new joint, assuring that it moves through a normal range of motion without dislocating. Sometimes, patients with badly deformed or damaged hips may not be able to regain full range of motion and must adjust to limited movement.

Regaining mobility after surgery takes time, the surgeons point out. Most patients are bedridden for several days but are walking — with crutches and supervision — within one week. Mrs. Cronin was on her feet with help in four days.

Earlier hip replacement patients convalesced in the hospital for three or four weeks, Dr. Ruys says. Mrs. Cronin, benefitting from recent medical advances, was home in 15 days.

Another increasingly common joint surgery involves replacing all or part of the knee, recommended as a last resort when cartilage, bone or ligament damage creates severe knee pain or disfunction.

Generally, the incision is made along the inside of the patella or kneecap although an incision along the outside of the knee may also be needed. The surgeon moves the patella to one side and marks the position of the implant parts. He then shapes the bones above and below the joint to insert the new parts, testing them before cementing them into place.

In some cases, where the surgeon finds that the joint's function may be greatly improved or knee pain reduced with a new kneecap, it can be accomplished through the same incision after the joint is replaced.

After either hip or knee replacement surgery, patients are ordered to use two crutches, not to become over-fatigued, and not to flex the new joint more than 90 degrees. At six weeks, x-rays are taken of the new joint to see if crutches can be discarded and activities expanded.

Even though laboratory tests have found these bionic joints amazingly durable under physical stress, only patient use over a period of years can determine how well the man-made part will stand the test of time, the orthopedic surgeons explain. In most cases, however, the plastic and metal implants are functioning for at least 15 years. Repair surgery may be necessary if the cement — a material that found its way into orthopedics after its use in dentstry for many years — loosens, allowing implant parts to erode away the surrounding bone.

New experimental "cementless" joints that fit snugly into place under pressure are being tested but are not yet routinely used.

Since December, orthopedic surgeons at the University of of California at San Francisco have been experimenting with a new cementless ceramic hip that is expected to last a lifetime. In 31 patients from 21 to 70 years of age, so far there have been no allergic reactions to the prosthesis.

During the surgery, the surgeon cuts grooves into the patient's pelvic bone matching grooves on the outside of the prosthesis so that the implant can be screwed into place, according to Dr. William R. Murray, chairman of orthpedic surgery. New bone growth fills in any existing gaps in the grooves.

Constant stress on the hip joint causes the cement in standard joints to loosen in about 25 percent of all patients, many requiring repeat surgery, Murray says.

Since a great amount of bleeding can occur in joint replacement surgery, patients are usually asked to give a pint of their own blood at the hospital prior to the

PULLOUT

operation for use in the operating room if needed.

The key to successful joint replacement, Katz ways, is sterility. Sequoia Hospital was the first hospital in Northern California 11 years ago — and still the only one in this area — to install a self-contained laminar flow surgical unit in which overhead filters replace the air every 10 seconds. Hospital personnel call the orthopedic surgical unit "the greenhouse" because of the greenish tint created by its transparent plexiglass walls.

The surgeons and nurses wear bacteria-proof suits, complete with astronaut-style bubble masks and air-conditioning hoses so that their own breath is discharged outside the unit.

Joint replacements pose more risk of infection than any other surgery because so much bone and muscle is exposed to the ouside world, Katz explained. The greenhouse reduces patient risk of infection to a rate of less than one percent compared to as high as 3 to 4 percent where laminar air flow rooms are not available, Katz contends.

Other risks, all of which rarely occur, include blood clots in the lungs or brain, nerve damage and excessive bleeding, Ruys says.

Orthopedic surgeons are reluctant to implant new joints in children, Katz notes. Youngsters are more likely to subject their joints to extreme wear and tear, requiring a replacement sooner than in adults. The risk of the procedure increases with every subsequent joint replacement as scar tissue develops. The patient's own original joint can never be returned once it is removed. "You burn your bridges behind you when you do this," Ruys says. "We are hesitant to do something so radical with someone very young." However, rheumatoid arthritis is one condition in which joint replacement in children is sometimes justified.

Since the greenhouse opened, Sequoia has performed 500 joint replacements — 350 hips, 120 knees, seven ankles and 23 revisions of previous operations. Ankles are less successful because of the weight-bearing burden placed on the new joint while elbows — not yet implanted at Sequoia — are hampered by constant rotation and flexion, Katz says.

Mrs. Cronin is attending physical therapy three times a week and expects to switch to a cane next week. She's thrilled to remove the ¼-inch lift she had to wear in her shoe when her degenerated joint shortened her right leg about ½-inch.

Joint replacement is not for everyone with severe joint pain. Some patients will do well with canes, crutches and anti-inflammatory medications to prolong the life of the natural joint, Katz says.

"The patient who is a good candidate is one with pain of a disabling nature," the surgeon said. Ruys adds that they are careful not to set up false expectations about these man-made body parts.

He warns candidates for joint replacement that increased strength, range of motion, and the ability to walk at a normal gait all "depend entirely on you." Attitude, he says, "makes all the difference in the world."

"I tell them straight out that the best I can offer them is relief of pain. Beyond that, everything else is gravy," Ruys says.

090

Peninsula Hospital and Medical Center
Blue Room
Monday and Friday at 8:00 and 9:00 a.m.
Special Showings by Request
For Information Call Ext. 375

Credit Information on Back Panel

NCME Medical TV Guide

Complete Program

Genetics for the Generalist

46 minutes (in color)

with Pomeroy Sinnock, Ph.D., Director; Clareann Bunker, genetic associate; William Bromley, M.D., F.A.A.O.O.; Morris Lambdin, M.D., F.A.A.P.; and Thomas Roderick, Ph.D., geneticist; all from the Genetics Counseling Center, Ellsworth, Maine.

This three-part program demonstrates clinically the five modes of inheritance of genetic abnormalities. Included are case demonstrations of:

- Dominant and Recessive Inheritance
- X-Linked and Chromosomal Disorders
- Multifactorial Inheritance

Self-Assessment Quiz

To receive continuing education credit, you must complete the self-assessment quiz below and return it to NCME.

CASE PROBLEM #1. Bonnie B., a girl of fourteen, came to a gynecologist for evaluation of very heavy menstrual flow. History revealed that Bonnie had had several severe nosebleeds during the first few years of her life. Approximately 2½ years before this visit, Bonnie had severe bleeding following an attempted tonsillectomy. This was resolved without treatment, and no diagnosis was made at that time.

Because of a history of severe nosebleeds in other members of the family, the gynecologist suspected a genetic problem and referred Bonnie for genetic evaluation.

The family history revealed that Bonnie's father has a history of severe nosebleeds, and Bonnie's brother also has nosebleeds. Factor VIII testing on the father revealed 13½% activity, a very low level. Both the father and the son have a prolonged bleeding time, and Bonnie has a slightly prolonged bleeding time. There was no history of any joint bleeds. No further family history was possible on Mr. B.'s side as he was adopted. Inquiry on the mother's side of the family revealed no evidence of bleeding disorder. Sketch Bonnie's pedigree.

1. Which of the following statements most likely applies to Bonnie B.?

a. The condition is sex-linked classical hemophilia.
b. The condition is recessively-inherited thrombocytopenia.
c. The condition is dominantly-inherited von Willebrand's disease.

2. Assuming von Willebrand's, how would you counsel Bonnie about her risks in future pregnancies?

a. One-half of her offspring will be affected.
b. With each pregnancy, there is a 50% risk that the offspring will be affected.
c. Only her male children may be affected.

CASE PROBLEM #2. Carol S., 27, was referred to the Genetic Counseling Center by her obstetrician. She had had four miscarriages and an 8-month stillbirth. Her obstetrician could find no obstetric abnormalities and was concerned that the miscarriages might be due to a genetic problem.

Carol had one sister who had three children and no miscarriages. Another sister had two miscarriages, two 8-month stillbirths and two living children, one with a heart defect. Her mother had only four living children out of nine pregnancies; her grandmother had no known miscarriages. Her great-grandmother had several miscarriages. Sketch Carol's pedigree.

Carol's peripheral blood karyotype revealed that she had an apparently balanced translocation in which the short arms of chromosome 10 had broken off and attached to the long arms of chromosome 13; 46, XX, t(10;13) (p11; q34).

3. Which of the following statement(s) does not apply?

a. Balanced translocation carriers are likely to have reproductive problems.
b. Peripheral blood karyotypes should be recommended for other family members.
c. Carol should be treated with a new drug to prevent abortions.
d. Carol has a normal amount of chromosome material, but arrangement of this material on chromosomes is abnormal.

4. Which of the following options could be presented to this family?

a. amniocentesis/prenatal diagnosis.
b. birth control methods.
c. sterilization.
d. all of the above.

CASE PROBLEM #3. Mary H. was a 47-year-old, height 42 inches, short-trunk dwarf who was referred for genetic counseling after a suicide attempt. The hospital psychologist learned that a great deal of her distress was related to short stature and also to the same condition in the patient's daughter. The daughter, Linda, age 20, height 44 inches, was engaged to be married, and the mother was greatly worried about her daughter's childbearing risks. Mary also had a son, who was normal.

The prior diagnosis in this case was Morquio's syndrome. Morquio's is characterized by typical symptoms of short trunk, marked growth retardation, diffuse corneal clouding, and characteristic X-ray changes. Lifespan is shortened and patients fail to reproduce. Morquio's is a recessive condition.

These patients had many of the symptoms of Morquio's syndrome upon external examination. However, physical examination of Mary and Linda revealed no signs of corneal clouding or abnormal heart sounds. Further evidence against the diagnosis of Morquio's was Mary's age and her reproductive competence.

In this case childhood X-rays may be much more informative than adult X-rays. Early X-rays were not available for Mary. However, Linda had been hospitalized many times for surgery to correct dislocated knees. Examination of Linda's early X-rays revealed changes characteristic of spondyloepiphyseal dysplasia, a dominantly-inherited disease.

5. On the basis of the pedigree, which mode(s) of inheritance can probably be excluded?

a. sex-linked.
b. dominant.
c. recessive.
d. sex-linked and recessive.

---

6. A couple has two children; one with cystic fibrosis and one normal. The chance that the next child will be normal is:

a. 0. b. ¼. c. ½. d. ¾.

7. All of the following but one are characteristic of autosomal recessive disorders:

a. No family history.
b. Parents are often related.
c. Only males are affected.
d. Both parents of an affected individual are carriers.

8. If a normal sister of a CF child marries a relative, her risk of bearing a CF child is:

a. increased over that if she married a non-relative.
b. decreased over that if she married a non-relative.
c. not changed from that if she married a non-relative.
d. ⅔.

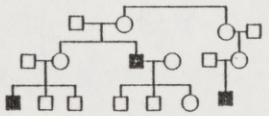
9. The chance that each pregnancy of a female with Marfan's syndrome will result in a child with Marfan's is:

a. 0. b. 50%. c. 25%. d. 5%.

10. A condition that appears every generation and seems to affect both males and females is most likely inherited as a:

a. dominant. b. recessive. c. chromosomal. d. not inherited.

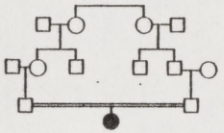
11. A family with retinitis pigmentosa gives you the following family history:



This pattern of inheritance is suggestive of:

a. dominant. b. X-linked. c. recessive. d. multifactorial.

12. Another family with RP gives this history:



The mode of inheritance in this family is most likely:

a. dominant. b. X-linked. c. recessive. d. multifactorial.

13. Down's syndrome is caused by:

a. recessive gene.
b. extra chromosomal material.
c. dominant gene.
d. excessive aspirin ingestion during first 4 weeks of pregnancy.

14. Which disorder cannot be reliably diagnosed prenatally?

a. Tay-Sachs disease.
b. Cystic fibrosis.
c. Down's syndrome and most other chromosomal abnormalities.
d. Meningomyelocele/anencephaly.

15. Most congenital malformations likely to be encountered by physicians are:

a. environmentally caused.
b. multifactorial in origin.
c. simple genetic (recessive, dominant, X-linked) diseases.
d. chromosomal disorders.

16. After the birth of one child with a neural tube defect, the chance that the next child will also have such a defect is:

a. 0. b. about 5%. c. 25%. d. 50%.

THE NETWORK NCME FOR CONTINUING MEDICAL EDUCATION
15 Columbus Circle, New York 10023

BUSINESS REPLY MAIL
NO POSTAGE STAMP NECESSARY IF MAILED IN THE UNITED STATES

POSTAGE WILL BE PAID BY:

FIRST CLASS
PERMIT
NEW

17. Which of the following is not characteristic of X-linked recessive traits?
    a. females rarely affected. c. carried by the female.
    b. mostly males affected. d. "male-to-male" transmission.
18. A translocation carrier 45, XX t(14;21) will expect to have:
    a. only normal children. b. only Down's children.
    c. some normal, some carriers, some Down's.
    d. only translocation carriers.
19. Amniocentesis is usually done during:
    a. first six weeks of pregnancy. c. 20th-24th week.
    b. 14th-16th week. d. last month of pregnancy.
20. Karyotypes are usually done from:
    a. urine. b. saliva. c. peripheral blood. d. throat culture.

The programs on this reel meet the criteria for credit on an hour-for-hour basis in Category 5(a) toward the Physician's Recognition Award of the AMA. For credit in the AOA program, consult your hospital D.M.E.

Self-Assessment Quiz

See Questions on Inside Pages

To receive continuing education credit you must complete and return this self-assessment quiz. Enter your Social Security number, hospital code number, and the date in the spaces provided below. Then refold the TV Guide to expose NCME's address and return the quiz to NCME.

SOCIAL SECURITY NUMBER _____

Hospital Code Number _____
(Number above Hospital name on front cover)

Date _____

Upcoming Programs

Rational Use of Antibiotics in Surgical Patients
Terminal Cancer:
The Hospice Approach to Pain Control
The Hospice Approach to the Family

Answers to Self-Assessment Quiz

1. c; 2. b; 3. c; 4. d; 5. a; 6. d; 7. c; 8. a; 9. b; 10. a; 11. b; 12. c; 13. b; 14. b; 15. b; 16. b; 17. d; 18. c; 19. b; 20. c.

The Network for Continuing Medical Education is a service link...

090

Peninsula Hospital and Medical Center
Blue Room
Monday and Friday at 8:00 and 9:00 a.m.
Special Showings by Request
For Information Call Ext. 375

Credit Information on Back Panel

NCME
Medical TV Guide
for March through March 20 1977

17. Which of the following is not characteristic of X-linked recessive traits?
    a. females rarely affected. c. carried by the female.
    b. mostly males affected. d. "male-to-male" transmission.
18. A translocation carrier 45, XX t(14;21) will expect to have:
    a. only normal children. b. only Down's children.
    c. some normal, some carriers, some Down's.
    d. only translocation carriers.
19. Amniocentesis is usually done during:
    a. first six weeks of pregnancy. c. 20th-24th week.
    b. 14th-16th week. d. last month of pregnancy.
20. Karyotypes are usually done from:
    a. urine. b. saliva. c. peripheral blood. d. throat culture.

The programs on this reel meet the criteria for credit on an hour-for-hour basis in Category 5(a) toward the Physician's Recognition Award of the AMA. For credit in the AOA program, consult your hospital D.M.E.

Self-Assessment Quiz

See Questions on Inside Pages

To receive continuing education credit you must complete and return this self-assessment quiz. Enter your Social Security number, hospital code number, and the date in the spaces provided below. Then refold the TV Guide to expose NCME's address and return the quiz to NCME.

SOCIAL SECURITY NUMBER _____

Hospital Code Number _____
(Number above Hospital name on front cover)

Date _____

Upcoming Programs

Rational Use of Antibiotics in Surgical Patients
Terminal Cancer:
The Hospice Approach to Pain Control
The Hospice Approach to the Family

Answers to Self-Assessment Quiz

1. c; 2. b; 3. c; 4. d; 5. a; 6. d; 7. c; 8. a; 9. b; 10. a; 11. b; 12. c; 13. b; 14. b; 15. b; 16. b; 17. d; 18. c; 19. b; 20. c.

The Network for Continuing Medical Education
is a service [illegible]

Growth Hormone Made at UC Here

By Robert Gillette
Science Writer

The human growth hormone, a chemical that governs the rate of a child's development and numerous other body functions, has been duplicated in the laboratory by two biochemists at the University of California in San Francisco.

Their discovery paves the way for large scale treatment of dwarfism in children, and it opens a new avenue of research in cancer — a form of abnormal tissue growth in which the hormone may be implicated.

Dr. Philip R. Lee, chancellor of UC's San Francisco campus, hailed the achievement as "one of the most important developments to come from this campus."

"We have an accomplishment that will help us better understand human growth and protein metabolism," Dr. Lee said. "This is life."

Credit for the first production of artificial human growth hormone — abbreviated HGH—belongs to Dr. Choh Hao Li, a professor of biochemistry, and Dr. Donald H. Yamashiro, a research biochemist in Dr. Li's laboratory.

—From Page 1

So for the Chinese born Li, often spoken of by his colleagues as a prime candidate for a Nobel Prize, the achievement marks the summit of a 32 year career devoted to isolating, analyzing, synthesizing hormones produced by the pituitary gland — a pea-sized organ at the base of the brain which controls so many living processes that it is called the body's "master gland."

Four Years

Laboratory tests show that the few thousandths of an ounce of HGH produced by Dr. Li are 5 to 10 percent as potent as the natural chemical. Synthesizing this tiny amount of HGH took four years, Dr. Li said. It is made up of chains of 188 amino acids, the constituents of protein, making it the most complicated protein ever copied by man.

Its immense importance to human life, Dr. Li explained in a news conference today, is demonstrated by the range of influence it is believed to have on the body.

Studies in animals, he said, suggest that besides controlling growth rates, it influences the release of fat into the blood stream and thus may be implicated in coronary artery disease.

In animals, growth hormone also influences healing of fractures and wounds, the level of resistance to infection and the activity of male and female sex hormones. HGH is known to govern development of mammary glands in women and their production of milk.

Dwarfism

Natural HGH is already being used to treat about 1000 children around the nation who suffer from dwarfism. But it must be painstakingly extracted from human pituitaries donated by persons after death. Each gland gives up only a few thousandths of an ounce of hormone, enough for one daily treatment of a child.

Synthesis of the hormone makes mass production possible, although this probably will not occur for at least five more years, Chancellor Lee said.

Between 10,000 and 50,000 children suffer from types of dwarfism which could conceivably be treated by HGH.

Beyond that immediate application, Dr. Lee speculated, artificial forms of HGH may prove useful in treatment of cancer, in controlling coronary artery disease and in enhancing resistance to infection.

How one family copes with achondroplasia

Betty Elder, liaison assistant for short stature at the Johns Hopkins division of medical genetics, reports she sometimes establishes rapport with new families by saying, "I understand how you feel. My 10-year-old son is an achondroplastic dwarf."

The son, Charles, is now three feet, two inches tall, with an estimated adult height of four feet, two inches.

When he was born, he was identified as having hydrocephalus. At three months he was operated on for a subdural hematoma. "The doctors first thought he'd be blind, deaf, retarded, and unable to walk, so the fact that he was going to be short was the least of our concerns," says Mrs. Elder. To date, Charles has had six brain procedures.

Despite physical impairments that include constrictions in his elbows, bow legs, a floating left eye and limited dexterity, Charles keeps up scholastically with his classmates in the fourth grade of a regular Baltimore County public school.

The Elders keep a duplicate set of schoolbooks at home so that he doesn't have to tote a heavy load back and forth. In the cafeteria line, he depends on a friend to hand him juice or ice cream. He's able to use a bathroom sized for kindergarten-age children; the bathroom for the older children is difficult to manage.

Charles plays a drum in the school orchestra and is on a Little League team, although he plays with a younger group. When he joined the Cub Scouts, the national organization made a uniform especially for him. The Elders have drawn the line at his use of a skateboard because of possible head injuries.

He wears regular child's size clothing that Mrs. Elder modifies. She cuts 10 inches off pants legs, takes sleeves out of the armholes and repositions them, and replaces snaps with Velcro tabs. Charles wears a hard to locate EEEEE shoe. Finding the right styles isn't easy: Charles doesn't want garments with cartoon characters on them —clothes designed with a younger child in mind.

The family home has few modifications for Charles, but there are stepstools around, and sticks hanging on doorknobs for turning lights on and off.

The Elders have a daughter who's 12 and, at five feet, two inches, of average stature. Mrs. Elder worries that Charles seems to get the most attention and her daughter just extra responsibilities. She had to insist that the older child not be assigned as her brother's "protector" on the school bus and instead be allowed to sit with her own friends.

Mrs. Elder says she doesn't feel offended when strangers ask questions about Charles. She does get upset "when mothers see their child staring and yank him away instead of giving him the explanation he deserves."

For Charles, the Elders have become involved with Little People of America. Says Mrs. Elder: "We want our son to have successful adult dwarfs as role models and to achieve all that he's capable of." ■

Coping in a big world

TIMES TRIBUNE
Wednesday, February 27, 1985—

Times Tribune staff photo by Joe Melena

Alfred and Harriet Stickney have kitchen appliances made to their scale, but other proportions of their home, such as the doorway behind them, obviously are for taller people. Nevertheless, they say, dwarfs can lead normal lives.

Sense of humor helps couple from San Bruno

By Carlos Vidal Greth
Special to the Times Tribune

In some amusement parks there are barriers set in front of the faster, more dangerous rides. If you can pass under the bar without ruffling your hairdo, you aren't allowed aboard.

If you can imagine living in a world where you have to pass a similar sort of height test every day, then you can begin to understand what it means to be a dwarf.

It also will help you appreciate the situation of Alfred and Harriet Stickney, a Peninsula couple who manage to handle social and cultural prejudices and barriers with courage, grace and a sense of wry humor.

The Stickneys are national mailing coordinators for the Little People of America (LPA), a 4,000-strong, voluntary organization dedicated to helping people of short stature. The basic requirement is that you must be 4-foot-10 or under to belong.

The Stickneys qualify easily. Alfred, who stands 4-foot-6 in his stocking feet, towers over his wife Harriet, a mere 4-foot-2.

"We're among the tall ones in the organization," Harriet Stickney said with a laugh. "We stand in the back row in group pictures."

For about 17 years, they've lived in an ordinary three-bedroom, ranch-style house in the quiet community of San Bruno. Strolling through the living room in the front of the house, you wouldn't deduce that little people live here, except for the fact the coffee table is strewn with scrapbooks filled with newspaper clippings and photos about the organization and dwarfs in general used by the Stickneys for family counseling.

The only extensive modifications are in the kitchen. The sink, counter space and the electric range are only about three feet off the ground. The shelves are set at an expected height, however, and the Stickneys have learned to wield an aluminum stepladder with considerable dexterity.

It is only when they leave the house that they encounter inconveniences. Harriet Stickney can't reach the mailbox facing the street. They both have trouble negotiating the steep steps into public buses.

"Grocery shopping can be a real pain," said Harriet Stickney, who is the more outgoing of the two. "I'm a great shopper of sales." Items on the first two or three shelves present no problems. Using a telescoping, hooked pointer, she knocks desired items above that range off the shelf, and either she or Alfred must quickly catch them.

"We're very careful with glass jars, bottles of oil and things like that," she said, "but we haven't dropped anything yet."

"Fortunately," Alfred Stickney added, "we've indirectly benefited from accommodations that have been made for people in wheelchairs, like ramps and lower pay telephones."

Their ingenuity reflects one of the positive aspects of being a little person. "We're adapters," Harriet Stickney said. "We do what we have to do."

Alfred Stickney, a federally licensed airplane mechanic and maintenance planner for United Airlines, was adamant on one point. "We want everyone to know that little people can drive, work and bring home a paycheck. I mean, we have friends shorter than we are who own their own plane and fly it."

They both reacted negatively when asked about entertainers in the Little People of America, which was founded by film and television star Billy Barty in Reno in 1957.

"We used to bristle when people assumed we were entertainers or comic wrestlers," Harriet Stickney said. "Over the years, we've relaxed a bit. Less than 3 percent of our members are in show business. Actually, we encourage the younger members to seek an occupation other than acting. There just aren't that many opportunities in Hollywood any more."

She indicated that when casting directors do call looking for little people, the younger members nevertheless like to take the jobs for the excitement and easy money. "But only on a temporary basis," she emphasized.

Times Tribune staff photo by Joe Melen

Height is no barrier to friendship, Alfred and Harriet Stickney have found. On a sunny day, they chat with friends Caroline and Herman Kundera, who live across the street from them.

Among the most important services the Little People of America provides is the counseling of families with dwarf children, or "little littles." Participation of the entire family is encouraged.

"Everybody is affected," said Harriet Stickney, a retired schoolteacher. "The terms 'big brother or sister' lose all meaning. We've spoken to groups from kindergarten to college age, but grade schools are our best audiences.

"We also provide support for the parents. When you have a child who's different, you really have to work hard at not putting guilt trips on yourself or on other people.

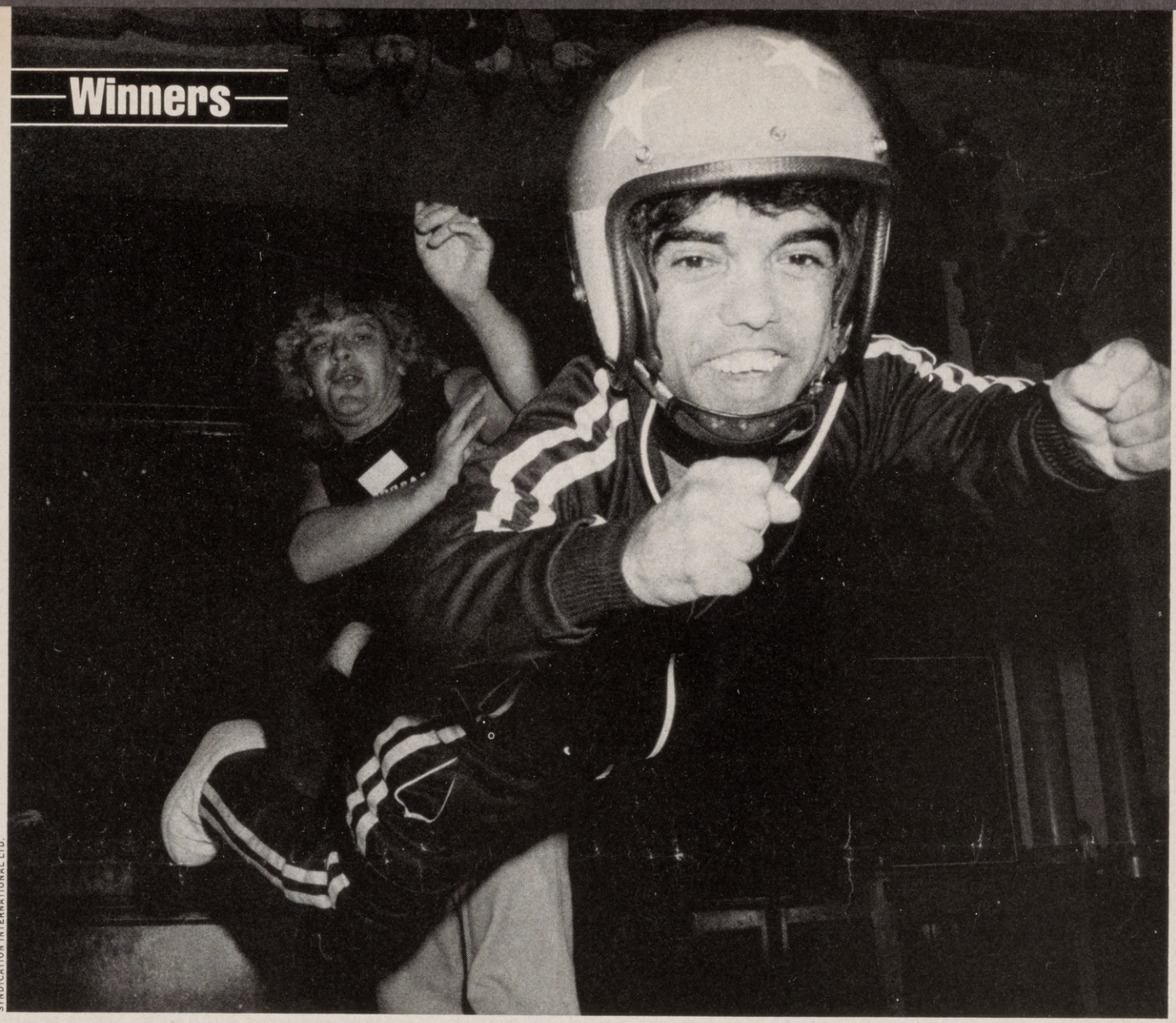
"Having a dwarf child is not necessarily the same as having a handicapped child," she said, explaining that there are about 100 types of dwarfs with all levels of physical conditions. "But let's face it, when a mother is told she has a dwarf baby boy or girl, she doesn't say, 'Oh, goody!' "

Little People of America sponsors annual conventions that have been held in Reno, Boston and, last year, in St. Louis. In 1985, it plans to meet in Puerto Vallarta.

"The first time you attend is traumatic," Alfred Stickney said. "It's like you're seeing yourself in the mirror. The world is cut down to your size all of a sudden. You get used to it. There's a lot of socializing and dancing every night. It's a rare opportunity for young little people to meet other little people."

The LPA publishes a flier ending with a thought that could very well describe the Stickneys. It reads: "A little person can live in two worlds — a small world and an average-size world. A person who finds happiness in both has nothing to lose."

Clearly, Alfred and Harriet Stickney have gained much and lost nothing.



SYNDICATION INTERNATIONAL LTD.

Jimmy Leonard launches Lenny for a good cause. The contests have raised $10,000 for charities, including $750 for Live Aid.

YET ANOTHER REASON WHY THE SUN NEVER SETS ON THE BRITISH EMPIRE: DWARF-THROWING CONTESTS

If Lenny the Giant, a British dwarf, ever had a stiff upper lip, he doesn't have it anymore. For the past several months he has encouraged large people to throw him long distances, face first. This ingenious but controversial activity, appropriately named "dwarf-throwing," reached its zenith in the British Isles last week when Jimmy Leonard, a truck driver and bouncer, heaved Lenny across 11 feet, five inches of the Worcester public house in Sutton to capture the all-important British Dwarf-Throwing Championships.

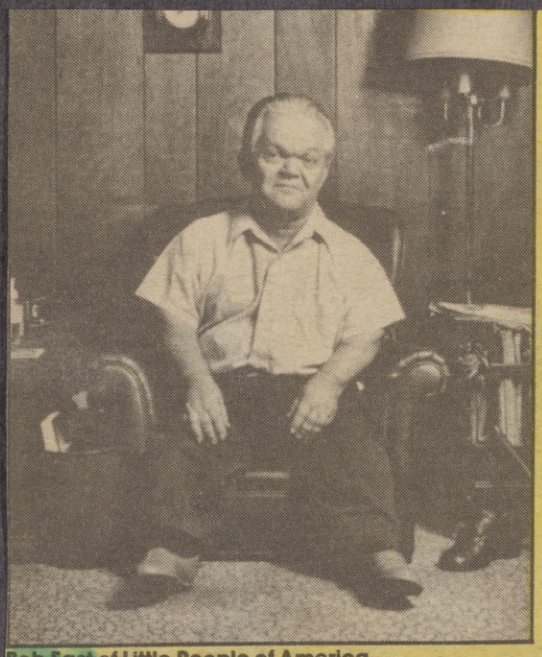
Almost anyone can hold a dwarf-throwing contest, providing he has an agreeable dwarf—and Lenny is that. When not orbiting barrooms, he appears with his comedy group, the Oddballs, often doing a skit in which a woman is called from the audience to change the diaper of an oversize dummy baby. At the last moment, Lenny substitutes. One can only imagine the fun.

Sometimes Lenny, 29, longs for a higher calling. That's when he straps on harness, crash helmet and knee and elbow pads. Contestants grab the harness, swing him three times and heave him onto a pile of mattresses.

Nobody expects too much out of an airborne dwarf—the aerodynamics are terrible—but the throw that won the British championship was positively Lilliputian. In Australia, where dwarf-throwing is said to have originated, a record heave of 30 feet has been claimed, although participating dwarfs might be smaller than the 4′4″, 98-pound Lenny. Says Lenny, rising to the defense of Britannia, "I think they must have been throwing inflatable dolls."

Dwarf-throwing is not without its detractors. Jack Ashley, a Labor member of Parliament, called the championships "extremely degrading to all concerned." Replies Lenny, "I used to work on an assembly line at an electronics factory—that's where I really felt degraded." □

THE SAN FRANCISCO
BayGuardian
PUBLISHED EVERY WEDNESDAY, MARCH 6 TO 13, 1985. VOL. 19 NO. 20.



Bob East of Little People of America

'Don't call me midget'

Local Color goes to a meeting of the Bay Area's Little People

BY LONNY SHAVELSON

A planned dwarf-throwing contest by hefty bouncers has enraged Australia's Little Peoples Association.

Organizers said the winner in the competition . . . will be the bouncer who throws a 4-foot-1 dwarf known as "Wee Robbie" the longest distance . . . Stephen Hobbs, president of the Little Peoples Association, said the contest was insulting and took dwarfs back to the days when they made fools of themselves in sideshows.

— Reuters (as quoted in the SF Chronicle, Feb. 27, 1985)

I don't want no Short People
Don't want no Short People
Don't want no Short People
'Round here.

— "Short People," by Randy Newman
(All quotes from the song are used by permission of Warner Brothers Records.)

Daniel Margulies, 32, is a four-foot-eight-inch mechanical engineer from Benicia. As an adolescent, at four-foot-four-inches, doctors told him he would catch up to the height of his classmates within a couple of years. "All I had to do was make it through one more day," Daniel remembers, "and everything would be OK."

At 17, though, doctors told Daniel he would grow no taller. "I freaked out," he says. "I had absolutely no idea what it was like to be a dwarf, even though I had in fact been one." He didn't even bother asking for dates. "Girls in high school are very hung up on looks," Daniel says. He met only one other dwarf, but they did not get along. "I think his defense mechanism was hostility," Daniel recalls. "He may even be five-foot-two-inches by now, I don't know."

They got little baby legs
And they stand so low
You got to pick 'em up
Just to say hello.

Daniel is a "Little Person." "Dwarf" is acceptable, "midget" is not. And if you're really with it, "L.P." is best. At my first Little People gathering, not being a dwarf, I thought I must be a "Big Person." I was soon reminded that I am an "Average Person."

The only physical characteristic common to all dwarfs is a height of less than four-foot-ten-inches. There are many types of dwarfism, with most caused by bone growth disorders. However, two general types can be distinguished: proportionate and disproportionate. Proportionate dwarfs are small in size but "normal" in body shape. Disproportionate dwarfs are small in size, but "normal" in body shape. Disproportionate dwarfs have a normal-sized head and torso with short arms and legs. A child born to a dwarf might be a dwarf or average-sized, depending on the type of dwarfism and the height of the other parent. And genetic mutations can occur so that average-sized parents have a dwarf child.

Short People got nobody
Short People got nobody
Short People got nobody
To love.

Daniel joined Little People of America soon after high school. He remembers traveling to an LPA national convention in Oakland with some Little People friends. "We caused a real sight," he says. "People wouldn't believe we weren't with a circus." One dwarf told Daniel he wouldn't travel with a group, because everyone would notice they were dwarfs. "I'm telling you, they notice anyway," Daniel told him.

When they arrived at the Oakland Hilton, there were more than 200 Little People there. Daniel remembers this as the high point of his life. "Man, I knew I really had it made now," he says. "I was the tallest one in the room." He met a four-foot senior engineer for Texas Instruments, and suddenly realized he could do anything. "My whole self-esteem changed dramatically," Daniel says. He received a degree in mechanical engineering in 1974, at a time when he says the job market was "wide open." Seventeen resumes went out, and 17 companies invited him to interview. None offered a job.

They got little noses
And tiny little teeth
They wear platform shoes
On their nasty little feet.

Before World War II, circuses were about the only place where groups of dwarfs could be found. But the war effort needed people who could fit into tight spaces to build ships and airplanes. With dozens of dwarfs working in Bay Area shipyards, there were many marriages and friendships. But at the end of the war, they returned to their isolation.

It wasn't until 1957 that an organization was started for dwarfs. The name, "Little People of America," was taken from a vaudeville song:

Oh, the good Lord loves us you can see,
'Cause he made so many just like you and me,
Built the whole world then rested,
So that He'd be free,
To keep making little people like you and me.

The new organization immediately formed committees. The food committee tackled the problem of culinary employees making remarks such as, "What will you have, Sonny?" and patting the heads of Little People they were serving. A telephone booth committee lobbied for glass paneling on the lower half of phone booths to alert a big person that a dwarf was inside.

If World War II was a big event for Little People, the Vietnam War helped their cause even more. "A large group of men came back in wheelchairs who had not grown up feeling subhuman, and they expected things," says Daniel. Suddenly there were lower elevator buttons and lower public telephones. It so happens that a dwarf standing is about the same size as a person sitting in a wheelchair. Years after the first LPA committees formed, things started to move.

They got little cars
That go beep, beep, beep
They got little voices
Goin' peep, peep, peep.

Ann Cupolo Carrillo, three-foot-five-inches, was a teenager when she first realized she wasn't just short. "It hit strong and bad," she says. "Every time I'd go outside, somebody would laugh at me. I'd cry and cry. I remember walking in the streets of New York. I was three-feet-four-inches and I was scared. I decided to go to school and get my mind to grow."

Ann was especially saddened by the thought that she'd never marry. But she began dating a classmate who was a dwarf. "People thought we were cute together," Ann says. They married, but it did not work out. "We were very different people," she explains.

Ann moved to Berkeley and went to her first LPA convention. "I needed to confront it once and for all," she says. "I had to refocus my eyes — there were hundreds of people at my level. I wasn't looked at as weird but as a possibility for a date — as a sexual object. I loved it."

When Ann met Steve, who is average-sized, she thought he was attractive. But the chance of going out with him didn't even occur to her. When Steve asked for her phone number, she felt embarrassed, flustered and excited. "The issue of being short was more my problem than his," Ann says. Today, after four years of marriage, the height issue is still an occasional problem for them. For months, the people next door were sure Ann and Steve were brother and sister. And Ann is frequently told how "special" Steve must be.

One of Ann's close friends is Jessica, another Little Person. "With Jessica, there's a sense of knowing unspoken feelings," Ann says. She and Jessica can discuss problems common only to dwarf women, such as an average-sized man's fears of injuring a dwarf when first making love with her, or their own past fears of men with fetishes for small women. And only Jessica is comfortable enough to get Ann's attention in a crowd by yelling, "Hey midget!"

UNIQUE BOY SEEKS UNIQUE GIRL

Straight WM, 23, 3'6", 75 lbs., law student...outgoing personality and sense of humor. Seeks special woman 18-26 who will see me for myself instead of my height. Want either casual or serious romantic relationship.

Bay Guardian personal ad, 2/6/85

In Little People of America, women outnumber men by about one third. Many dwarfs say it is harder for men to adjust to being small. One dwarf woman, asked where the men are, replied, "Oh, they're out there trying to catch the big ones."

But for Daniel, dating is limited to members of Little People of America. "I'm not comfortable dating average-sized women," he says. "Maybe I'm not fully adjusted." Daniel's average-sized friends tell him about going to singles bars to meet women. "They don't really understand my situation," Daniel says. "The thing an average-sized person can never really understand is that every second of my life I'm a Little Person. Every average person I meet first sees me as a Little Person. Only if given enough time do I become an individual."

They got grubby little fingers
And dirty little minds
They're gonna get you every time

At my first Little People gathering, I didn't squat down, as I would when talking to a child. I may be an average person, but I am Sensitive. Standing upright, I was informed that the Little People had their necks "cranked up" to talk to me. So I tried squatting. Five minutes into a conversation, a dwarf said I looked uncomfortable. I was instructed to put my "bottom on the floor," and the Little People could either join me or remain standing. "That's drawing attention to your smallness," I protested. "We know we're small, you know we're small. Might as well be comfortable," the dwarf told me.

Yvette Farrington with her parents.

Yvette Farrington, three-foot-two-inches tall, 14 years old and beautifully blonde, was in the second grade when she first noticed everyone else getting tall. "I felt a little funny," Yvette says, "but I got used to it pretty quick." Being a member of LPA since she was 18 months old had a lot to do with the smooth transition.

Bob East, a 63-year-old member of LPA, fills in what Yvette doesn't remember. "When she was born," East recalls, "a doctor unfamiliar with dwarfs told her parents she wouldn't walk, she'd never have hair and she'd be retarded. They were shaken." Another doctor arranged a meeting with LPA. "I didn't see anything wrong with Yvette," East says. "I told them, 'she is smart, she's not going to be crippled.' We were the first ones who ever told them that. And she is bright, she's got hair, and her parents are good strong parents."

East is familiar with family problems related to size. He has two average-sized children from separate marriages to Little People. When his son Jon first went to school, the boy was ashamed to let anyone see his parents. Bob encouraged Jon to join the Cub Scouts, and then Bob and his wife became the den leaders. "That just turned it around," Bob says.

When Bob joined LPA, Jon became friends with Connie, one of the dwarf children who attended meetings with her parents. After Jon returned from Vietnam, he and Connie decided to marry. "I wasn't for it," Bob says. "The Little Person can get hurt." But Jon convinced him the marriage would work. Jon and Connie now have an average-sized, eight-year-old daughter and are expecting another child this summer. The family is still discussing whether they want the baby to be average-sized or a dwarf.

Bob now finds LPA most important for the children. "It's just being there, so they know they're not alone in the world," he says.

'I remember walking in the streets of New York. I was three-feet-four-inches and I was scared. I decided to go to school and get my mind to grow.'

—Ann Cupolo Carrillo

The LPA Yearbook has more than 100 photographs documenting membership and events. If you look carefully, you can find a photograph of Kenny Brown, who is black. In LPA, dwarfism appears to be a caucasian disorder. "It just worked out that way," says Daniel, now LPA national treasurer. "Forgetting I'm a dwarf, I'm white and middle class. For me to go into the barrio and get people to cough up their dwarfs — it's impossible." For a black dwarf at an LPA function, Daniel says, "In one way, he's very much at home, but in another way he's not."

LPA meetings give dwarfs a sense of acceptance and comfort, which they often don't find in their work places or neighborhoods.

Similarly, for many dwarfs, it is possible, but difficult, to live in both the full-size and dwarf worlds. It does have its price: Daniel says he is still not used to people coming over to say "Hi" just to see if he can talk. Daniel did eventually find his job as a mechanical engineer, however. After the 17 rejections (one company told him, "You just don't fit our corporate image"), he was finally offered a job, sight unseen, at a Navy shipyard. When he arrived at work, his boss said, "You know this is a Navy shipyard? I don't think you're going to make it." Daniel replied, "I really hadn't planned to quit this soon."

"That was the first and last time the issue came up," he says. And only occasionally does his boss come by to ask for a favor. Sometimes there are leaky pipes, stuck behind a bulkhead, that would cost thousands of dollars to remove. Would Daniel mind squeezing in there to fix them. ■

Ann Cupolo Carrillo and husband Steve.

No small matter

San Jose Mercury News, Sunday morning, March 24, 1985

Dawn Abbey, a 3-foot-11 senior at Yerba Buena High School in San Jose, in her specially designed 5-foot-high attic bedroom.

'Big people in little packages' reshape image of inferiority

By David E. Early
Mercury News Staff Writer

"DON'T call me a midget," says Harriet Stickney. "I consider it a derogatory term."

At 4-foot-2, Stickney delivers this warning with the voice of a scowling giant. She is a pleasant, accommodating woman with a delightfully rowdy laugh. But whenever the opportunity comes to clear up any misconceptions about her people — little people — Stickney does it with a certain gusto.

"I admit there are some days I just don't want to go outside and hear the whispers and the comments. Things like, 'Look at that midget.' Or kids saying, 'Mommie, look at the little woman.' But I know the only way to change people is for us to get out there. To show people we might be small but we're also pretty terrific human beings."

Stickney is the president of the San Francisco Bay Area chapter of Little People of America Inc., a self-help organization founded in 1957 by actor Billy Barty. It is a social, psychological and medical resource center for people of short stature, commonly known as dwarfs. It has a national membership of about 5,000. The Bay Area LPA represents about 100 dwarfs plus 100 families of dwarf children.

"In the 22 years I've been in LPA, I think we have expanded the horizons enough so many people realize we can do more than be circus entertainers and newspaper vendors," says Stickney, who lives in San Bruno with her 4-foot-6 husband, Al. "But we need people to know just because we are small doesn't mean we cannot have families, have homes, be independent, and hold down jobs."

Connie East, 33, is a living testament to how normal life can be for a little person. Every day she commutes on BART from her home in Hayward to San Francisco's Mount Zion Hospital, where she is a medical secretary. She is no more or less afraid of the crowds and the big city than anyone else.

"I was almost mugged one time," says the 4-foot-3 East matter-of-factly. "I was coming back from the bank to my job when it happened. I was able to fight the guy off and ended up biting him on the hand. He didn't get a thing."

Her husband is average size but his parents are both little people. Connie's parents and siblings were all average size, as was her first child. But in June Connie will have a baby doctors say will be a dwarf. She loves her life and says she will make sure her dwarf child will have a rich, loving life.

Size doesn't count

"Look at us as people. Don't look at our size — that is not an indication of our hearts and abilities."

However, because many people do look at their size, little people say "heightism" haunts them in tall proportions And for dwarfs, the problems are compounded by:

- Vast employment discrimination on all levels of the work force. Little people find it difficult to become everything from waiters to managers. And now they say big companies are telling little people they don't fit the corporate image.
- Parents who pull their children away from little people when their curious children point and ask questions. By doing this, parents are tacitly telling their children something is wrong with little people.
- The notion that little people are primarily employed in side shows, circuses and as professional wrestlers. In reality, little people tend to overcompensate at work and can be found in just about all walks of life.
- The belief that dwarfs are necessarily retarded or have mental capacities equal to their physical stature. The amount of retardation is no greater in little people.
- The anxiety average-sized people have around little people. Little people say many (especially employers) feel they can't speak frankly or demand a lot of work from them. Many feel little people are easily offended or embarrassed.

Dwarf-tossing contests

Recently, little people have been vocal because of widely circulated stories about a dwarf-tossing contest in Sydney, Australia. Hefty bouncers competed to see who could throw "Wee Robbie" Randall the farthest.

The 4-foot-1 Randall says that participating in the event showed he had a sense of humor about his condition. But a spokesman for LPA says the contest was "insulting and took dwarfs back to the days when they made fools of themselves in sideshows."

Barty, in San Francisco recently to talk about LPA and life as a little person, says the contest is just another example of the kind of mistreatment that can result if ignorance about little people is allowed to flourish. He called the contest sick, dehumanizing and dangerous.

"I mean, what would stop some drunk teen-agers at a party from seeing that story and deciding that throwing a little person around might be fun," says Barty, 60, probably one of the most famous dwarfs in America. "Considering all the problems little people have with their bones, the idea is so terrible I don't even want to discuss it."

Barty says little people meet stature-related problems every minute of every day in ways average-sized people need to understand. And, conversely, he says many little people have to face up to their condition and learn not to see themselves as ugly and unwanted and cursed.

A 17-year-old Costa Mesa dwarf committed suicide in November 1983, leaving behind a note which ended with the words: "I guess I don't love myself enough or something. I just couldn't handle the life God gave me."

Her father, Richard Crandall, a dwarfwas so shaken by the incident that he started the Short Stature Foundation, which aspires to become a lobbying group for little people.

The 3-foot-9 Barty admits that when you're small life is a series of attitudes and physical barriers that must be overcome. Prejudice is tough, but so are things like telephone booths, grocery stores, hotel closets, bar stools, elevators and cafeterias.

That's why LPA wants to encourage a few physical modifications in society (there has been an increase in accessible public telephones) and earn the understanding and respect of average-sized people. Such changes could mean a great improvement in the quality of life for those Barty calls "the big people in little packages."

Cap Carpenter — Mercury New

Harriet Stickney (right) and her neighbor, Chris Schindler, chat in the Stickneys' kitchen, remodeled to fit the Stickneys' smaller proportions.

Little-person tricks

While puffing along on his tiny, bent legs, Barty says the Fairmont Hotel should have moved him and his entourage out of rooms on the 19th floor and "12 miles from the lobby." The button in the elevator for the 19th floor was higher than six feet.

"The bell boy asked me what these were for," says Barty, fingering a package of unsharpened pencils he ordered from room service. "We use the eraser to push the buttons on the elevator because it's mushy like a finger. When you're a little person, learning something like that is very important." But even his pencil wouldn't reach the 19th-floor button.

Inside his closet at the Fairmont, Barty displayed another little-person trick. His tiny, custom-made clothes were on wire hangers he specially requested from the hotel. Those hangers were hung on the bottom of the closet's regular hangers and therefore within his reach.

Modification is a way of life for little people. Specially tailored clothes and shoes can be ordered from firms in Hong Kong. And it is not unusual for little people to redesign their homes. The Stickneys' kitchen, for example, has lower counters so Harriet and Al can cook and wash dishes with ease.

Dawn Abbey, 18, a senior at Yerba Buena High School in San Jose, has a bedroom in the attic of her parents' home. The 5-foot-high room has custom-fit shelves and closets. There is a small mirror and sink, a chair and a twin bed. Beneath the skylight is a fluffy menagerie of stuffed animals.

"I've been up here for 3½ years now, and even though there are two extra bedrooms downstairs, I like this room because it was specially designed for me and I'm comfortable here," says the 3-foot-11 Abbey, who drives her own 1979 Honda with the help of pedal extensions.

Abbey agrees with Barty's bromide that "the biggest space barrier you have to conquer is between your ears." She says conquering that barrier usually begins in school when the little person watches classmates spurt ahead physically. At first little people endure teasing about their large heads, their stumpy legs, their short, plump fingers and their waddling walks.

Later, their unique size earns them a certain popular notoriety. Classmates are very friendly and genuinely protective. No one dares pick on them and they become the best-known person at school.

Although this popularity continues, another barrier is erected when it's time for dancing and dating.

"I have lots of friends, but sometimes it's hard seeing my friends going out on dates while I head on home," says Abbey. "When I want to talk about it I go to my parents or other little people I meet at LPA meetings. Those are the only people who really understand how I feel."

Difficult time

Adolescence is perhaps the most difficult time in little people's lives because it is a time that forces them to face up to their condition.

Andre Boursse, an affirmative-action officer for the Santa Clara County Transportation Agency, remembers that when he was in high school he thought he could make people forget his condition by succeeding on the gymnastics team.

"I figured I'd be a jock and that would be my key to fame, fortune, wine, women and song," says Boursse. He practiced every day on the still rings and ultimately won a state championship.

Little people plagued by myths and mysteries

But when the bleachers cleared and no fawning cheerleaders fell before his 4-foot-6-inch frame, Boursse was devastated. He realized real success with people would be earned if he became someone respected for his humor, personality, intellect and ability.

"If you feel bad about yourself it will come out and others will pick up on it and shy away from you," says Boursse, 36. "And if parents of a little person feel bad about themselves and their child, that attitude will come out and have an effect on the kid."

Stephanie's story

Perhaps that's why Trish Mayhugh of Livermore fought so hard to get her 7-year-old daughter, Stephanie, into public school. Mayhugh says she is proud of her little person and wants the whole world to know.

The school district feared for the girl because she has seckle syndrome, a form of dwarfism that makes her extremely tiny. There are only five other known cases.

At age 7, Stephanie is 26¾ inches tall (about four inches longer than this news page) and weighs 12½ pounds. Her palms are the size of postage stamps. Her voice is a happy, high-pitched squeak.

She looks like a perfectly proportioned doll that moves. When amazed gawkers call her a baby, Stephanie pipes up and proclaims, "I'm not a baby, I'm just a dwarf."

By the time her non-dwarf baby brother was 6 months old, he was too big for her to hold, says her mother. When Stephanie's father said, "Sorry, honey. You can't hold him because he is bigger than you are," Stephanie ran to her room and cried.

Still, today the child doctors said would be a vegetable attends first grade, wears her own tiny eyeglasses, sits in her own tiny desk and does school work from a tiny black board near her seat to accommodate her poor vision and her size.

"The thing I would tell anyone who has a dwarf child is to love that child and to keep on asking questions," says Mayhugh. "Stephanie has totally amazed us since she was born with all she has overcome. If we had listened to the doctors, she would be in an institution."

THERE are more than 100 types of dwarfism and each is considered to be a separate disease. According to Little People of America Inc., more than 82,000 dwarfs are born each year.

Ninety percent of all dwarfs are born to parents of average size and many have siblings of average size.

Not much is known about dwarfism. It is caused by a random mutation in the cartilage genes. Some rare cases of pituitary dwarfism can be treated with limited success using growth hormones. Last May scientists at the University of Chicago announced the discovery of the genetic defect that causes dwarfism. Still, they cautioned any treatment for dwarfism was many years away.

Many dwarfs experience frequent physical and medical problems. These include everything from sinus and eye troubles to arthritis and numerous skeletal and bone complications. They do not necessarily have shorter life spans, but the length and quality of their lives depends upon the type of dwarfism.

There are two major types of dwarfism:

- **Achondroplastic,** the most common type, is characterized by average-sized heads and torsos but unusually short arms and legs.
- **Hypopituitary,** caused by malfunctioning pituitary glands that produce an insufficient amount of growth hormone, results in small men and women with average proportions.

Another type, diastrophic, is an uncommon but more troublesome form of dwarfism. Diastrophic dwarfs experience severe complications with their limbs, especially hands, legs and feet. These people usually require many years of surgery and may often still require wheelchairs or crutches.

— David E. Early

notes. "Mythology abused us. The royal courts amused themselves at our expense. And circus and entertainment industries have promulgated the myth that most dwarfs work in show business. Nothing could be further from the truth."

She's a retired school teacher. He, a 30-year United veteran, is a federally licensed airplane mechanic and maintenance check planner.

While his short stature never was an obstacle to employment, he admits the irony of a man his size working on giant jets.

"Some years ago, I was standing on a step ladder working on a plane," he explains. "Beneath me, a 6-foot-2 friend was working on the hangar floor. We both had a good laugh and joked about switching jobs. But the point is, we were performing functions of our own expertise. Size had nothing to do with it.

"I didn't choose this profession to be the world's smallest maintenance check planner," he continues. "And Harriett didn't want a shot at the tiniest teacher award. Like anyone else, we play to our strengths, not our weaknesses."

That message comes across loud and clear when the Stickneys counsel families of dwarf children. It's a role they clearly cherish.

"Every family member is affected," Harriet says. "If the dwarf is the oldest child, the terms 'big brother' and 'big sister' lose all meaning. Parents need help working through their guilt, because friends don't exactly jump for joy when they learn about a dwarf baby. Parents experience real trauma and we need to educate them so that they can regroup and go on living."

Social and cultural prejudices are bad enough, but the real villain of this genetic mutation is dysplasia, the abnormal alignment of bones and muscles. There are two major categories of dwarfism—disproportionate, like the Stickneys, and proportionate. Within these two distinctions, however, lie more than 100 sub-categories, spanning all levels of physical development.

A proper diagnosis, therefore, is of the utmost importance. Johns Hopkins University Hospital in Baltimore is the grandfather of short stature programs, but the Stickneys also refer families to several clinics throughout the country.

"Having a dwarf child isn't necessarily the same as having a handicapped child," Harriet explains. "A precise diagnosis is mandatory to help children reach their full potential."

To say that dwarfs get the short end of the stick in this average-size world is no exaggeration. The Stickneys live in a three-bedroom ranch in San Bruno. Surprisingly, the only extensive modifications are in the kitchen, where sink, countertops and range are only three feet high.

But the real fun begins just outside their front door. Harriet can't reach the mailbox. And they both have trouble negotiating the steep steps of public buses. Grocery shopping is a pain. Products on the first three shelves are within reach, but above that, they need a telescopic hooked pointer to knock items off the shelf before they catch them.

"It's a constant juggling act," she notes. "But we haven't dropped anything yet."

Dwarfs have benefited from some handicap accommodations, such as wheelchair ramps and lower pay telephones. "But we still need to adapt," Al says. "We do what we have to do."

"While his short stature never was an obstacle to employment, he admits the irony of a man his size working on giant jets."

It's a big world—especially for dwarf Al Stickney, SFOOV. How he's meeting the challenge makes him someone you should know.

The Stickneys came to terms with their dwarfism long ago, though each had strikingly different childhoods. Harriet grew up on a Wisconsin dairy farm and enjoyed the small-town closeness of rural America. Al, an Army brat, moved around the country with his family. Both, however, had supportive parents and siblings.

Al tells of going to the circus as a young child. The show itself didn't faze him because he was more concerned with a dwarf he'd seen selling pencils near the big top.

"I couldn't understand why anyone would choose an occupation like that," he says. "I just couldn't relate."

In that respect, Stickney says dwarfs are different from other minorities. "If you're black or Hispanic, you can at least look to the members of your family and identify with their blackness or ethnic traditions. A dwarf can't always do that."

That's where LPA enters the picture. The organization has 12 districts through the U.S., including Alaska. Support groups meet locally, giving members the opportunity to meet on a regular basis. But the annual LPA convention is definitely the main event of the year.

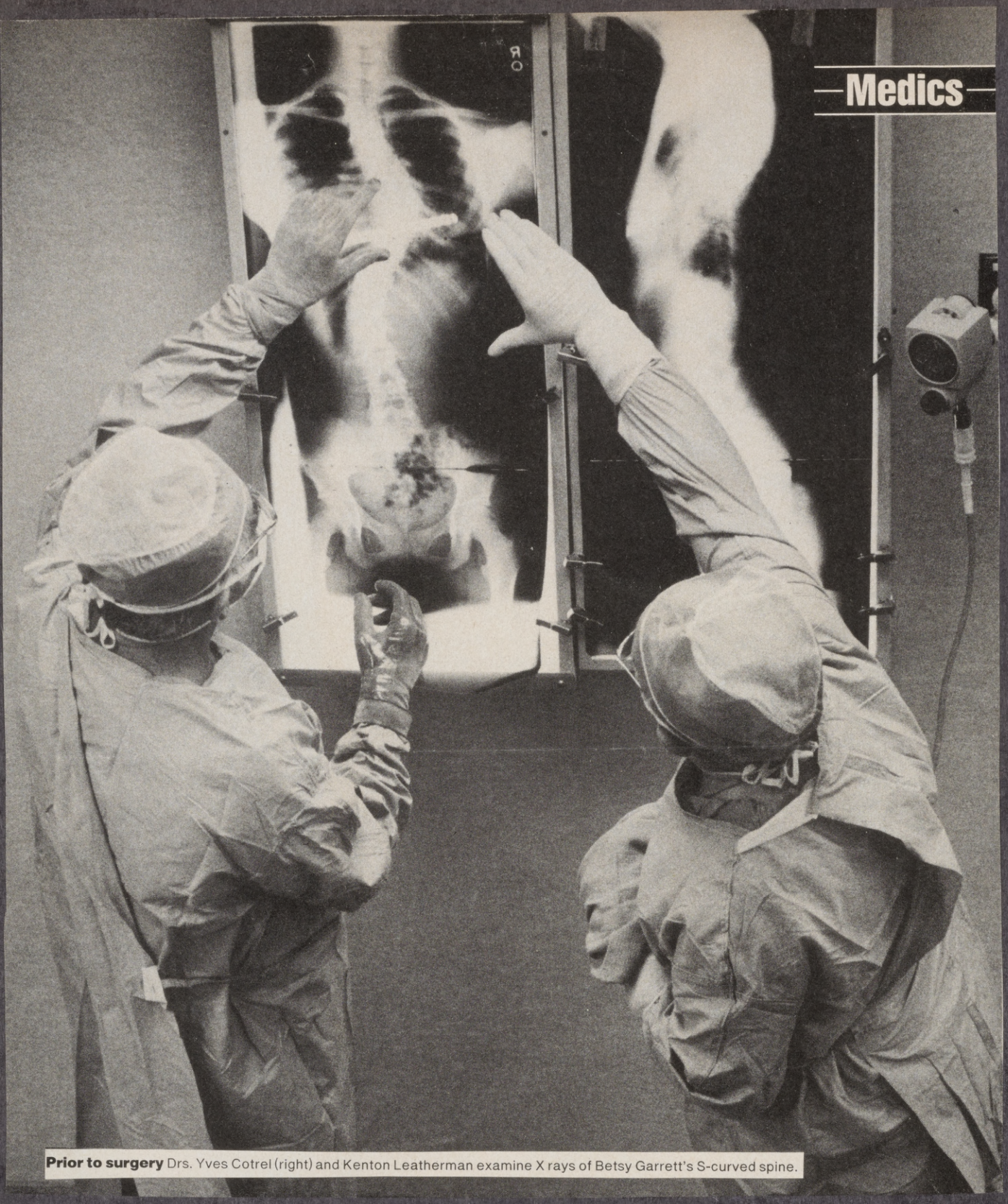
"Today it's like any other convention," Harriet says. "You walk into a hotel lobby and see old friends catching up on lost time."

"We're proud the young members can see us driving up to the hotel," Al adds. "So what if we need leg extenders? What the kids see is our independence. They learn firsthand that they can be self-supportive members of society."

Ask the Stickneys what they wish for future generations of dwarfs and they'll tell you the future is now.

"We're already seeing the fruits of our labors," Al says. "We have members in their teens and early '20s who have never known life without the love and support of the LPA. Their self-images and self-confidence are just tremendous. It's our dream come true."

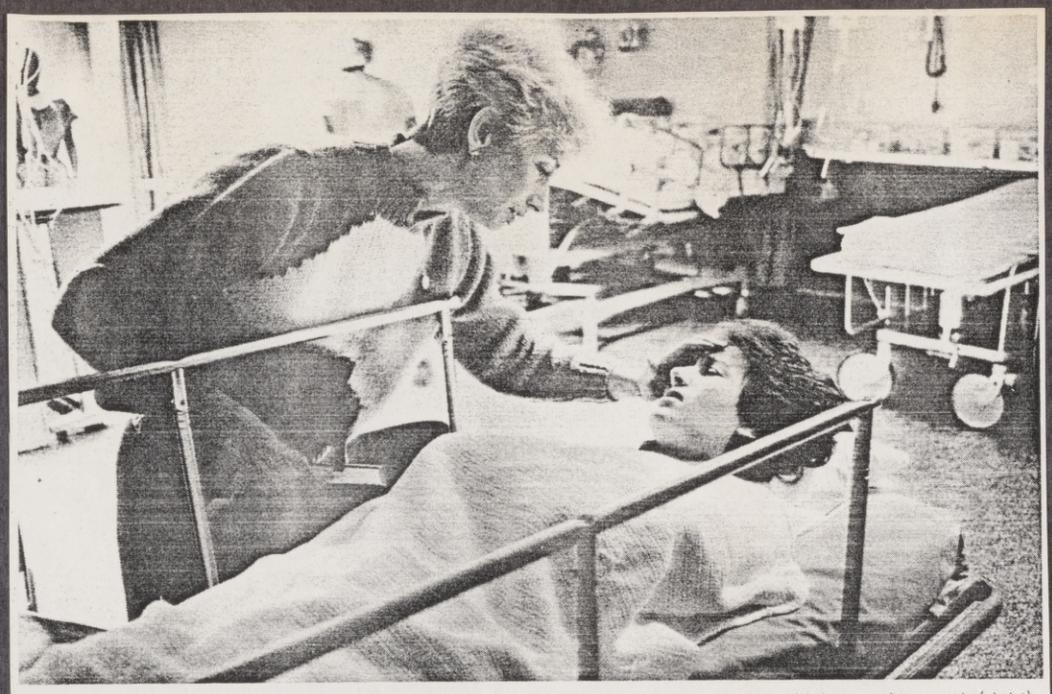
For more information on the LPA, write to the Stickneys, Little People of America, Inc., P.O. Box 633, San Bruno, Calif. 94066.



Prior to surgery Drs. Yves Cotrel (right) and Kenton Leatherman examine X rays of Betsy Garrett's S-curved spine.

A FRENCH DOCTOR PIONEERS A WAY TO CORRECT CROOKED SPINES

Betsy Garrett of Hodgenville, Ky. grew up as a poised, self-assured youngster who always stood and sat up straight. But a little more than three years ago, when she was 10, Betsy was given a health exam at her elementary school, and nurse Virginia Stewart noticed that one of Betsy's shoulders was higher than the other. From the girl's protruding shoulder blades, Stewart recognized that Betsy had a dangerous spinal deformity that could one



Andrea Garrett comforts daughter Betsy before her operation, during which one of two rods (right) is placed alongside the spine. The two steel supports will be fastened to the vertebrae by eight hooks.

day require major corrective surgery.

Her condition is called scoliosis, and it is not altogether rare. One in every 10 youngsters has some abnormal curvature of the spine. It is a defect that tends to run in families and affects school-age girls more than boys. In about a fifth of the cases, the children are born with the condition or develop it as a result of another disease, such as polio or muscular dystrophy. But for no apparent reason, in the large majority of instances scoliosis develops in otherwise healthy children, usually between the ages of 10 and 15.

Most scoliosis cases are mild. The more serious ones often can be treated through exercise, electrical stimulation or by wearing body braces. But in one out of 1,000 cases, the spinal curvature becomes so severe that it distorts the rib cage and impedes the growth and function of the heart and lungs. Physicians and parents cannot simply assume that the child "will grow out of it," warns Dr. Kenton D. Leatherman, 72, director of a spine center named for him at Louisville's Norton and Kosair Children's Hospitals. "Scoliosis patients have died of heart and lung failure."

Today 18 states require scoliosis screening in schools. A number of other school districts have voluntary programs with nurses or gym teachers checking students' spines. "With early diagnosis, surgery can be avoided in many cases," says Leatherman, who is also a professor of orthopedic surgery at the University of Louisville. But for Betsy Garrett, even prompt diagnosis could not stave off three years of discomfort that included experimental surgery developed in France.

When Betsy first came to Leatherman in 1981, he hoped that the simplest treatment would suffice. He recommended postural exercises for Betsy to do at home. "Unfortunately," she admits, "I didn't do them regularly." Her spine curvature worsened.

Back at the hospital, Betsy was fitted for a Milwaukee brace, a girdle-like device that went from her hips up to her chin, topped off with a neck ring. She cheerfully agreed to the contraption until she tried to pick an object off the floor—and failed. But after physical therapists showed her how to move—and after she saw other children in braces—"her whole attitude changed," says her mother, Andrea. "She was fine."

With her bulky brace on, Betsy could no longer fit into her size 3 clothes. She acquired a loose-fitting wardrobe: Jogging suits with baggy drawstring trousers proved especially adaptable. "Betsy was fantastic in accepting her situation," recalls nurse Virginia Stewart. "It's traumatic for a young girl to have to wear a Milwaukee brace. Her body image is so important at that age." Her teachers asked her schoolmates not to stare, and everyone cooperated. "My friends are kind of protective," says Betsy. "They wouldn't let anyone say anything about it."

For two years the brace was a fact of Betsy's life, night and day. It came off for a few hours each week only to enable her to bathe, to put on a dress for Sunday services at the First Baptist Church or to attend school dances. Yet Leatherman decided the brace was not accomplishing enough for Betsy to avoid eventual surgery.

There are currently several surgical options for scoliosis, most involving the permanent implantation of steel rods in the patient's back to straighten and support the deformed spine. The newest variation was developed by French spine surgeon Yves Cotrel, 60, and uses a complicated series of hooks together with a pair of cross-braced rods. The Cotrel technique has one obvious advantage over the other methods. After most types of spine surgery, patients must be encased in a body cast or brace for as long as six months. In contrast, the Cotrel variation provides such strong support along the spine that the cast is dispensed with and the patient can be up and walking four days following surgery.

After 135 successful operations in France, Dr. Cotrel, a longtime friend of Leatherman, demonstrated his technique in Louisville last September. In November Cotrel returned to Louisville to operate on a new group of patients—including Betsy Garrett.

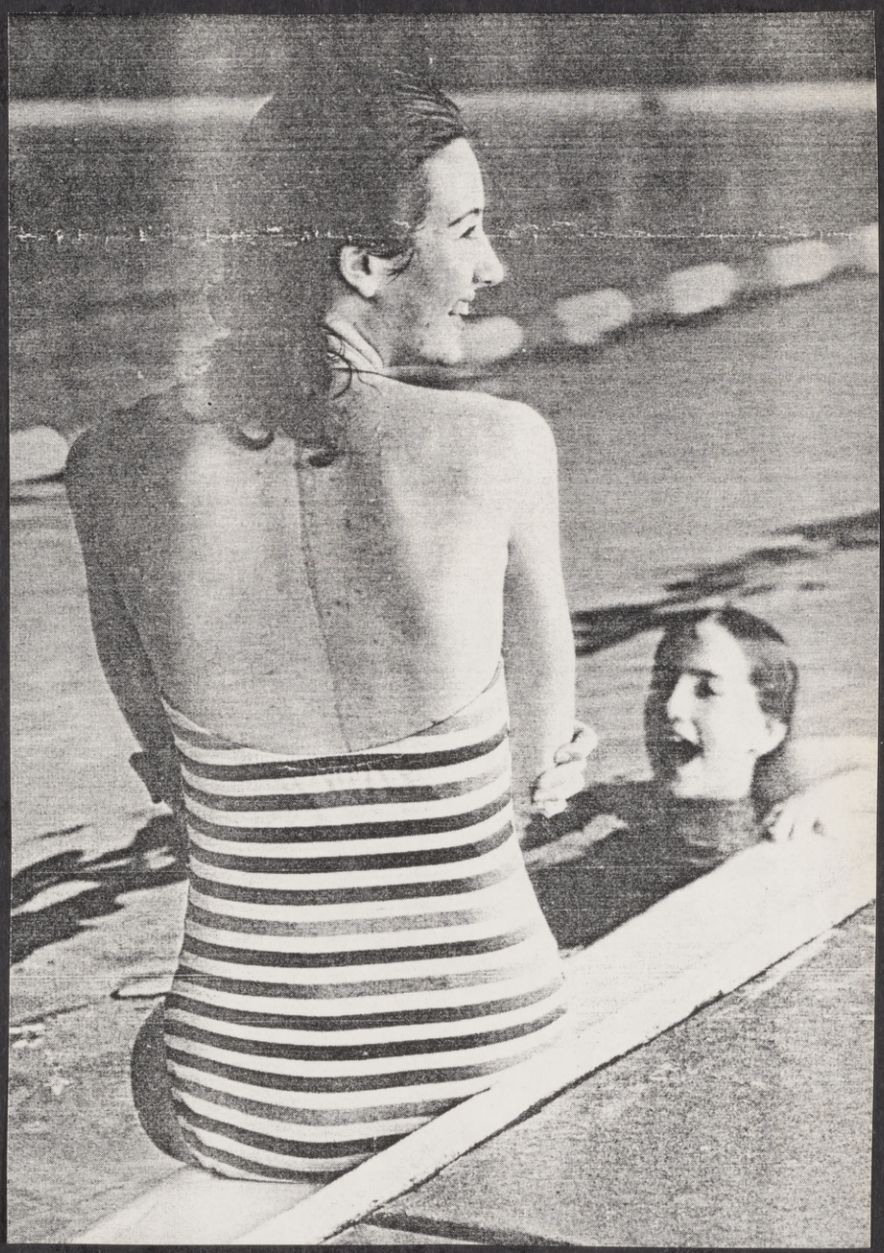
Her parents agreed to the surgery, and Betsy herself was remarkably calm about it, considering that she had undergone chest surgery only nine months earlier. At that time she had a steel plate inserted to expand her chest cavity so that her heart and lungs would have more room to grow (the plate was surgically removed in February). Still, she approached her new operation with no sense of dread, her mother says. "She seemed to feel, 'Oh, good, I finally get to throw my brace away.' "

Early on the morning of November 21, Cotrel and Leatherman meticulously studied full-length X rays of Betsy's spine to determine the placement of the hooks and rods. "It's a matter of where the hooks go and which hook will do what," Leatherman explained. Betsy was anesthetized at 7:44 a.m., and the tedious, four-hour operation began, during which her spinal cord was monitored against damage. Leatherman observed but did not participate in the surgery. At one point chips were removed from Betsy's pelvic bone and sprinkled on the spine so that it would fuse solidly. "Betsy will be able to bend and even do gymnastics," Leatherman cheerfully predicted. "Even when the spine is fused, patients can bend and put their fingers to their toes."

In the end, all of the doctors' hopes were borne out. Just three days after surgery, Betsy took her first steps, beginning with a walker and then unaided. Only 10 days later her parents drove her the 50 miles to Hodgenville and their antique-filled home, where without help Betsy climbed the stairs to her room with its four-poster bed. By January 10 she was back in class at LaRue County Junior High, and exercising at home to Carol Hensel records.

Today her life is normal. She swims at an indoor pool, plays the flute in the school band, practices the piano, and makes cookies for her sisters, Anna, 11, and Sally, 7. After school she visits her parents, Eric and Andrea, at the family-owned furniture store, and joins friends for movies in nearby Elizabethtown. One thing about Betsy has changed: She is noticeably taller. Before surgery she was 5′4″. By the time of her 14th birthday on February 22, Betsy, standing straight, noted gleefully, "I grew two inches in just two months."

GIOVANNA BREU



With sister Anna (in pool), Betsy, her incision healed, says she's aware of the rods in her back only when she "jerks real quick."

He may be small in physical stature, but Dennis Calonico is big in the eyes of his players.

The game's the thing

No, this isn't the National Football League. These kids are involved in the North Peninsula Intermediate League, a flag football program for boys in the seventh and eighth grades. The Carey School in San Mateo, a small, private institution, is a member of the league. Its coach, Dennis Calonico, 33, says the competition is healthy and gives boys a taste of football, sans tackling and heavy contact. His players ended the 1984 season with a 1-5 record. The school mustered up 11 players, nine of whom play at any one time. Calonico, a graduate of Serra High School in San Mateo, has been a teacher and coach at Carey for 10 years.

AMES SCIENTIST TESTS HORMONE

Hope For Dwarfism Victims

By DALE F. MEAD
Staff Writer

MOFFETT FIELD — Thousands of children whose stunted growth goes untreated eventually may be helped by a discovery made by an Ames Research Center scientist.

It may be easier than anyone imagined to synthesize a growth hormone that not only alleviates dwarfism but may speed recovery from severe injuries like burns, physiologist Richard E. Grindeland has found.

Today more than 10,000 youngsters suffer dwarfism, caused by a lack of the growth hormone somatotropin.

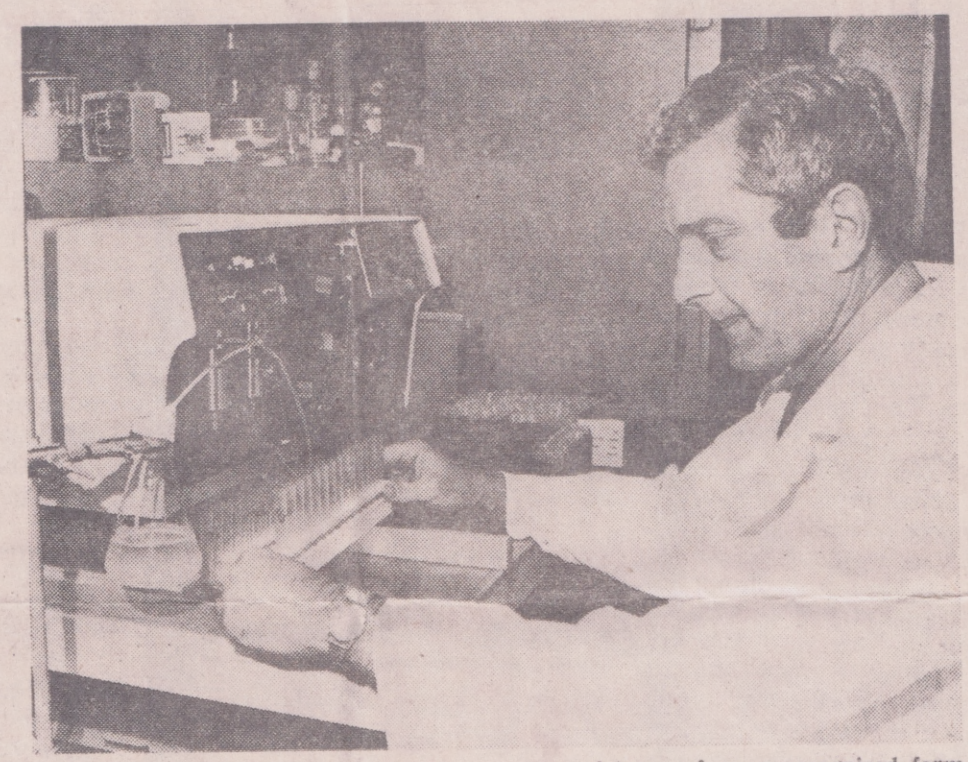
Some of them are treated with supplementary doses of the hormone, extracted from the pituitary glands of cadavers. But only 70-80,000 cadavers are available each year, providing enough of the hormone to treat roughly 600 afflicted youngsters.

So dire is the need for somatotropin that there isn't any available for research to see how effective it can be for speeding the repair of injuries — even though animal tests point to great promise.

The compound is so complex that medical researchers have not been able to find a way to mass-produce it synthetically at reasonable cost.

But Grindeland's findings suggest that the experts have been looking at the wrong stuff all along.

The chemcal found in the pituitary gland is in a state for storage, and must be chemically transformed by the body into a simpler, active form before it can act, he explained.



GROWING CONCERN — Ames Research Center physiologist Richard Grindeland, who recently documented the existence of an unrecognized form of growth hormone, at work in his laboratory. —Staff Photo

Not only that, but the conventional methods of measuring the hormone in the blood often prove misleading because the active form is not measured.

Grindeland got into the problem while trying to understand how astronauts would respond biologically to stress in space.

The growth hormone aids growth in children, but for adults it is secreted — and changed from its storage state — during fasting, exposure to cold, emotional stress or physical exercise.

Since astronauts undergo high emotional stress but don't exercise much in space, the NASA researcher needed to know whether the output of the hormone needs to be increased or decreased to avert medical problems.

During the course of his research, Grindeland injected plasma into young rats whose pituitary glands had been removed, and their interrupted growth started again.

Yet the usual assay techniques indicated the hormone level in the blood of those rats was going down instead of up.

Currently he and a colleague in the Ames Biochemical Endocrinology Branch, Dr. Stanley Ellis, are trying to isolate pure samples of the active hormone from blood plasma.

Once the active form can be purified and its effects verified, medical experts will have a new, perhaps easier challenge before them: to find ways to manufacture the active hormone artificially.

If that can be done, not only will children suffering from dwarfism be able to grow to near-normal heights, but researchers then can delve into its impact for tissue repair. A new means for speeding recovery from burns and other severe injuries could result.

ITOYA

ART PROFOLIO

IA-12-8-36

China